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ABSTRACT

This compilation of essays and resources focuses on acceptance of children with disabilities and cooperation between parents and early intervention specialists. The compilation includes the following items written by Jan Spiegle-Mariska (sometimes cited as Jan Mariska): "Building Effective Parent/Professional Partnerships"; "What Parents Want from Early Intervention Professionals"; "What Parents Valued Most from Early Intervention Professionals"; "A Mom's Perspective on Early Intervention"; "The Risk of Divorce: What Parents Can Do To Help Themselves"; "When I Felt Really Bad, I Read a Book..." (cites inspirational quotations from numerous authors); "Skyriding" (a poem); and "Suggested Readings for Professionals and Families Seeking To Form Effective Partnerships." The guide also includes "Welcome to Holland" by Emily Perl Kingsley and "Acceptance Is Only the First Battle: How Some Parents of Young Handicapped Children Have Coped with Common Problems," a 43-page booklet by Susan Duffy and others that discusses advocacy, support groups, parent-professional relationships, and conflicting professional advice. The compilation concludes with a list of materials available from the CO-TEACH Preschool Program. (JDD)

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common ground

a series of essays for professionals and families who unite to help young children with special needs

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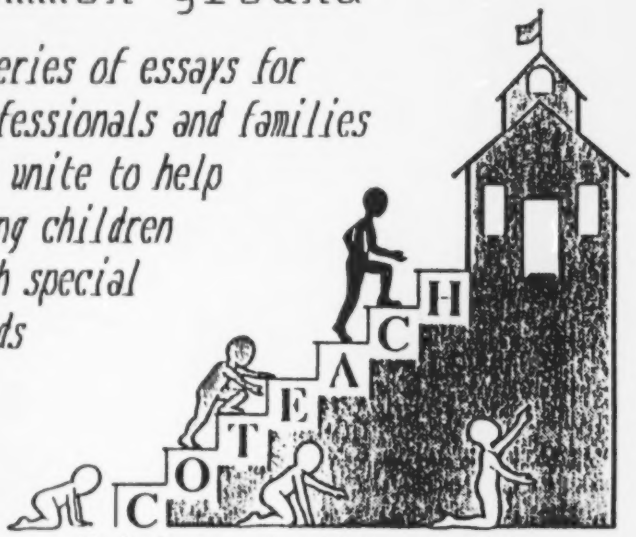

Early Intervention Makes the Difference

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BUILDING EFFECTIVE PARENT/PROFESSIONAL PARTNERSHIPS

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Special education professionals in the last few years have recognized that making parents an integral part of the planning/implementation process is essential as we go about the business of providing services to young children with special needs. We have begun to see that parents carry with them their own particular brand of expertise based on their intimate, day-to-day knowledge of their child, and that those insights and knowledge are a valuable asset to the team which serves a child's needs. Parents who have had positive experiences with early intervention services for their children have recognized professionals as the indispensable part of their lives that they must be if their children are to reach their full potential. Parents and professionals alike have begun to pay attention to the fact that **we need each other** in order to make the service delivery system work effectively.

So, how is it that we often end up at odds with one another? Why do parents so often seem to resent the professionals who provide the very services parents want so desperately for their children? Why is it that anger, hostility, and defensiveness color our relationships more than we would like? More specifically, how can the service delivery system for young children with handicaps be structured to diffuse those adversarial roles and enhance parent/professional partnerships? What factors form the basis for developing dynamic working relationships with parents?

I asked parents from my local support network, all of whom have had extensive experience with early intervention and school-based education programs, to respond to those questions. What follows is a summary of their thoughts and feelings, as well as some of my personal observations on how partnerships can be developed.

Primary among the catalysts which allow parent/professional partnerships to happen is **trust**. When parents feel trust in the professionals who serve their child, it does much to diffuse the confused emotional reactions that parents often face as they go about seeking and implementing services for their child.

It is vital for professionals to recognize and understand some of the feelings that parents experience as they come to terms with the fact of their child's handicapping condition. For a parent to seek "help" for their child is an admittance that help is needed. The very act of soliciting aid requires the parent to admit to themselves and "the world" that their child indeed has a problem.

For most parents, that is an excruciating step, one which reopens the wound inflicted when they first learned of their child's diagnosis. Simply picking up the phone to make the call asking for help is an act most parents recall as painful. Many admit to avoiding it as long as they could.

In some ways, the service delivery system seems to "set up" parents and professionals in antagonistic roles from the very beginning of the relationship. Since the "system" usually begins service provision with a formal developmental evaluation of the child, what parents immediately face after seeking services is a team of professionals likely to give them even more dismal news. They have already experienced a trauma most of us only know in our nightmares. They know a depth of sorrow few of us will ever fully understand. They are trying desperately to recover from the initial diagnosis and **to shield themselves and their families from more pain.** And, any evaluation, unless it totally contradicts the original diagnosis, **will inflict more pain.**

When parent\professional relationships start off on this basis, it is not difficult to understand why parents seem (and often are) hostile, uncommunicative, and resistant to the very help they are seeking. But, if parents can perceive, when they first meet with a professional, that the professional is a human being who clearly cares about and has their child's best interests at heart, it does much to dismantle all the "defense shields" that are in place. It lays the foundation for establishing a trusting relationship in which parents and professionals alike know they are members of a team with a common goal: to nurture the child's development.

From a parent's perspective, the first meeting (and perhaps, the first few) with professionals would ideally happen in a relaxed and comfortable setting. (For some parents, that means having the professional come to their home; for others that situation seems intrusive. It seems reasonable to **ask the parents** what would be the most comfortable for them.) There would be few, if any, forms to fill out. They would simply talk to the professional about their child; they would air their concerns and be asked for information. Their responses would be listened to with a great deal of attention. The professional would get down on the floor and play with their child. By their actions and responses to the child, the parent would be able to see that the

person providing services sees the child "first" and the handicap as secondary to the **human being.** (Modeling this attitude, by the way, is seen by parents who have "been there," as the single most effective helping strategy in aiding the parents themselves to accept their child's disability).

Filling out the forms and scheduling the formal evaluations would happen **after** the parents have been able to establish some rapport with the people who will, literally, be helping them raise their child. Thus, a situation which has the potential to seem very intrusive to the parents and family can be made to feel less so. It can be, instead, the foundation on which an effective relationship is formed. The most common comment of the parents I talked to went like this, "If I see acceptance of my child in the service provider, if it is obvious that they like my kid and that my kid likes them, then I will do everything in my power to make the relationship work. We may have to "agree to disagree" on some issues, but if I know the provider truly cares, that's what's most important to me."

The following items are things which parents would like professionals to consider **before** they meet with parents to set up a plan of service for the child. One mom suggested that it would be a wonderful thing if professionals would read this list before each and every meeting with a "new" family.

PARENTS SPEAK TO PROFESSIONALS

ITEM: By the time we get to you, many of us have been through the mill - emotionally, physically, and financially. Some of us have made "life or death" choices for our child. Many of us have dealt with at least one medical professional who did not feel our child was worth treating. We are probably in one of the stages of grief that are an inescapable part of bringing a child with a handicap into the world (shock, denial, anger, chronic sorrow, reorganization, equilibrium) (Kennell and Klaus, 1983). Those stages, by the way, are not a continuum which we move through and are done with. Many of the stages are revisited again and again as we work toward assimilating our child into our lives.

ITEM: Please understand that we experience conflicting emotions when we meet with you (through no fault of your own). Simply talking about our child is painful, and we are frightened about any transition our child and family is about to make. We also feel great relief because we know you represent hope and help for our child. It helps a lot if you find positive things to say about our child's potential, or even if you comment on long

eyelashes and pretty hair. That helps us to know you see our child as a human being, as opposed to a "problem."

ITEM: Understand that what is decided at any planning meeting will impact many parts of our lives. We have much to lose if services are less than adequate, and much to gain if they are optimum. To us this is not "just another meeting."

ITEM: We need to understand (if we don't already) that we are a valuable part of the team that will decide on the structure of services for our child. Your recognition of our "expertise" helps us to retain a sense of control over our lives that often gets lost somewhere in the system of service delivery.

ITEM: We need help to recognize that **we** are the experts on our particular child. We often think of ourselves as "just moms and dads," and do not fully realize the depth of knowledge that comes from parenting a child everyday. We have knowledge of learning styles and behavior patterns specific to our child that can be a valuable resource to the team that provides services.

ITEM: We need to feel that professional members of the team value our input. **Parents who are treated as equal and essential members of the team are much less likely to become defensive or combative. Parents usually get that way when we think no one is listening with any attention to what we say.**

ITEM: We know that you cannot "eliminate the negative", but we need you to "accentuate the positive" when you are assessing our child's development and potential. We need to understand that evaluative testing and "labels" are just tools we all use to make decisions and obtain services; that I.Q. numbers and diagnostic labels do not define who our kids are as human beings **in your eyes or in our own.**

ITEM: Complex diagnoses and educational strategies need to be explained to us in language a lay person can understand. Don't talk down to us, just routinely offer explanations of technical language.

ITEM: We need to be given continuing encouragement to ask about things we don't understand. Our emotional vulnerability does not always allow us to grasp what you say to us the first time we hear it. We can assimilate only so much information before the

defenses protecting us from "more hurt" automatically snap back into place.

ITEM: We need to feel that adequate time has been allocated for the meetings in which decisions about our child's life are made. (**One frequent and major complaint of parents who have been through early intervention programs is that meetings are often hurried or scheduled "back to back" with other meetings, so there is pressure to "get it done quickly."**) We see the decisions that are made in these meetings as momentous in our child's life, and we require time **during and after** the meetings to consider the consequences of what is decided. If papers need to be signed, please let us know it is our right to take them home to read in a less pressured atmosphere.

ITEM: More than anything else you do for us, we need you to be an enabling and empowering force in our lives - not someone who does things **to** our family or **for** our family, but someone who works **with** our family to help us obtain the skills we will need to make a healthy adaptation to the conditions which shape our lives. If you can help us to be informed consumers of services and good advocates for our child, you have given us skills we will need and use for a lifetime.

WHAT PARENTS WANT FROM EARLY INTERVENTION PROFESSIONALS

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The following "wish list" was compiled by ten families, all of whom have children with handicapping conditions, and all of whom have had extensive experience with home-based early intervention programs.

*Help us to see our child as a valuable human being who has a contribution to make to this world. (The best way to help us is to model that attitude yourself.)

*Whether we are single parents trying to cope with our kids, or couples facing our extraordinary circumstances together, help our families to stay together and function as a unit. Understand that whatever work you do with our child has an impact on ALL members of our family.

*Help us to see that personal and family happiness does not end with the diagnosis of an imperfect child.

*Help us to meet other parents who have stood in our shoes, survived, and gone on with their lives.

*Help us to nurture learning in our children, but do not strip us of our parenthood by asking us (or allowing us) to become therapists or behavioral researchers.

*Tell us when we are doing good things. Tell us often.

*Help us to see the difference between problems we can overcome and problems we must learn to cope with.

*Help us to see the need for respite time BEFORE a crisis happens.

*Help us to be effective advocates for our child. (For all of us, there have been times when we couldn't be good advocates, for whatever reason. Be an advocate for us at such times, or help us to find someone who can fill that role.)

*Know that parents are ALWAYS vulnerable people, because of the emotional stake we have in our child. Understand that emotion as a natural feeling for a parent to have about any child. Don't write us off as neurotic or hysterical parents because we have those feelings, and may sometimes have trouble keeping them in check.

*Understand that, for many parents, there are times when, for various reasons, we will chose not to follow some recommendation you have offered. Saying "no", selectively, to things which will not work in our lives right now is not an indication of lack of faith in your abilities. Most of the time saying "no" is a short term matter of survival. Don't take offense.

*Know that there are times when asking us to do one more thing that "only takes five minutes a day" is NOT a good idea. Be alert for signs of "burnout" - exhaustion, lack of ability to concentrate, apathy. When a parent says, "I don't know how much longer I can do this," what they probably mean is, "I CAN'T do this anymore!"

*There are parents who know the law, who are effective advocates, who have become de facto early intervention professionals. We all need to remember, however, that the best resource parents can bring to any parent/professional relationship is our intimate, day-to-day knowledge of our child. USE THAT RESOURCE.

WHAT PARENTS VALUED MOST FROM EARLY INTERVENTION PROFESSIONALS

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The thoughts and suggestions below are taken from conversations I have had with parents whose children have diverse handicapping conditions. Though they are, by no means, a scientific sampling of opinion, they are offered with the hope that they will be of value to professionals whose work brings them inside our families and our lives.

"My home trainer never wrote preplanned goals for my daughter. We wrote them together. She always believed that what I thought was important should be top priority for my child."

"If I thought my child was bored or frustrated with a task, my home trainer dropped it. Without question, he believed I was the person who knew my child best."

"When I thought it looked as if my child would need placement outside our home, our home trainer got me every resource available to help me keep him at home. I will never be able to repay her for helping me to see that, with help, we could keep our son with us."

"Our trainer found me another Mom with similar problems. That person has become my best friend. We couldn't cope without each other."

"My home trainer didn't just hand me a respite list. He took the time to find us a respite provider who understood and could handle my son's many needs. He did this at a time when I did not have the physical energy or emotional mindset to do it for myself."

"When we got picked up off the waiting list, my home trainer did not tell me respite was available IF I NEEDED IT. Instead, she filled out the forms, got me the money, and said "USE IT!" It was months later that I began to realize how essential "time away" is to my well being, and that of my family. Early interventionists should make this top priority."

"My home trainer got me the materials that I needed. When I asked for a book or a specific toy, she got it right away. Having to wait for things would have been maddening."

"My home trainer helped us to find the best possible foster placement for my son when I knew I could no longer cope."

"My home trainer never forces me to take data. She just teaches me how to play with my child. She always knows when its time to set the work aside and just talk to me."

"She was an advocate for us when we needed her to be. She found money for a hab aide when I couldn't have survived without one. She helped us deal with the medical crises. She got us the cheapest plane fares, made reservations, etc."

"Our person let my OTHER daughters know that they were valuable people, too. She was tolerant of their interruptions. She often brought them small gifts (a stick of gum) when she was bringing things for Sara. She saw their value in helping Sara to learn. SHE TAUGHT ME THAT SARA'S SISTERS WOULD BE HER MOST EFFECTIVE TEACHERS."

"She encouraged and supported my interest in helping other parents. She made me feel good about doing this, and that made me feel good about myself."

"Our trainer encouraged our participation in a support group. She understood what it meant for me to have a network of people around me who understood me, because they had stood in my shoes."

"Our trainer made sure that we knew our child's rights and our own under P.L. 94-142."

"My trainer loves my daughter. She isn't afraid to care. I believe her professionalism has not suffered for her having become personally involved. My experience tells my that professionals who don't allow themselves to care don't help families very much."

"Some professionals have trouble looking past whatever label is placed on a child, trouble dealing with the whole child, rather than the "problem." We, as parents, understand the need for labeling in order to obtain services. Past that, we see labels as being very limiting, and sometimes, damaging."

"My trainer cried with me when our daughter died. No one else knew what to say, or else they said it was "a blessing." I will never forget how healing it was to know that SOMEONE ELSE valued my child's life as much as I did."

One theme echoed again and again in my conversations with families who have been through early intervention programs. Above all, they valued a trainer/ teacher who treated the family as a unit, and not the handicapped child as a separate entity.

Like all children, children with handicaps grow and learn best within a stable, loving, and accepting family atmosphere. All the intervention programs in the world are of little use if life is filled with turmoil and stress for the family and/or the child. Helping parents to reach a BALANCE in serving their child's needs AND those of other family members goes a long way toward facilitating establishment of that nurturing atmosphere. Without that balance, parents find themselves in a never-ending state of having too much to do in too little time. Since divorce rates for parents of handicapped children are approaching 80%, I believe the basic and primary function of any family intervention on behalf of a handicapped child should be to help keep families from going under.

A MOM'S PERSPECTIVE ON EARLY INTERVENTION

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When I was asked to participate in this conference, I began to think about the experiences I have had with early intervention, (what was good, and what was not so good about it.) Slightly more than five years ago, on March 30, 1983, our third daughter, Sara, was born. Twenty-four hours later, I was told that she had Down Syndrome. I was fortunate in that our pediatrician put us in immediate contact with other parents of children with Down Syndrome. From them, I learned about the Comprehensive Developmental Center in Missoula, the agency in our area that provides home-based early intervention services.

When Sara was four days old, we began working with her, doing the exercises and stimulation programs recommended at our first home visit. We continued the data based programs on a daily basis until the winter of 1985, when Sara began to be served by the CO-TEACH Preschool Program on the University of Montana campus.

The day that Sara began at CO-TEACH stands out as a banner day in our minds because it marked the time when we became "free" to be simply parents to our daughter for the first time in her life. From day four we had been her therapists, her teachers, and her advocates. We remember that it felt remarkably wonderful to have some of those job titles lifted from our shoulders. We remember that our three other daughters (by then we had a fourth, wonderfully normal daughter, whose name is Hope, because that's what we did for nine months) were delighted that our lives no longer revolved around whether we got Sara's programs done on any particular day.

As Sara's mother, I remember the tremendous relief of knowing that Sara was getting everything she needed - **and that I wasn't the one who had to do it anymore.** I had, of course, heard about "burn out" by that time. I don't know that I recognized at that time, that what I was feeling was "burnt out." But, in retrospect, I most certainly was. We continued to be served by a home trainer for several months after Sara began CO-TEACH, and we still did (and do) a great deal of naturalistic teaching at home. But, the responsibility for Sara's education was now in someone else's hands.

For the first time in her life, I began to enjoy her for the **person** she was. I reveled in every accomplishment she made, and unlike before, that enjoyment was not tainted by the knowledge that when she finally achieved a goal, we would start all over again on the next step, the next day. Best of all, I had two and one-half glorious hours every afternoon that were mine. Before, if I sat down to read the newspaper or even took time to put on make-up, somewhere in the back of my mind there was always lurking the thought that time was being wasted; that I could, (maybe should), be working with Sara, that time was a horrible thing, that time lost today could not be recaptured. It was an oppressive thought with which to live on a daily (even hourly) basis.

For nearly three years I had been obsessed, and that obsession had done damage to me, to my relationship with my husband, to our other daughters, and to our family unit. Fortunately, for us, there had been a strong base; there had been a cohesive unit before Sara. The existence of her disability had stretched all the boundaries of that cohesion. But, for the time being, the boundaries had held.

When my obsession began to gnaw at everyone, they were always able to bring me back; most importantly, my husband was always able (with very compassionate and well chosen words) to make me see how far from home base I had drifted. I remember, at one point in time, seriously considering taking Sara and leaving my family, not because things were bad at home, but because my husband and my daughters had all become hindrances to what I wanted to do--focus every waking moment on Sara's development. When I told my husband about this thought, I remember clearly the look on his face. It was the look you might give a formerly sane person who had just suggested jumping the Grand Canyon on a motorized skateboard. The look was followed by a series of rational questions: "Where would that leave me? Where would that leave Jamie and Jess? Do you honestly want them to grow up without you?" Of course, that was not what I wanted. But, the forces that pulled on me every hour of every day were taking their toll. They were wounding my relationships with the people I value most. They were, at times, making me crazy.

So, where did this obsession come from? In large part, it came from who I was, from what "baggage" I had brought along with me from my life before Sara. I was a teacher. And, though I had never focused in my professional life on teaching children with special needs, I knew a lot about how "normal" kids learn. Time and time again, I was told by friends, family, and professionals how lucky Sara was to have me for a mother. In some ways, I guess I felt I had to be the person that everyone expected me to be. I had been good at my profession, had quit only because the pull of full-time motherhood was so strong in me. Now, I would be both mother and teacher. This child would need me more, would need me longer than my other kids would. I wanted desperately to be equal to the task of raising her.

I plunged headlong into that task. I read everything that had been written on Down Syndrome. I badgered my pediatrician and home trainer for more current information. I joined a support group and listened to what other parents were saying. I signed Sara up with CO-TEACH months before she was of acceptable age. I made myself a nuisance at the library. I counseled parents of newly diagnosed kids, lest they be given outdated data. I investigated vitamin therapy, sheep cell injection, and the Doman Method. And, I did learning programs and took data -- mountains of data. I was praised by my home trainer. She held me up as an example to other parents. If she suggested it, I did it. When the state sent its people to evaluate CDC, Sara and I were there to show them how wisely the money was being spent.

So, the obsession began with who I was. It was, however, fueled by professionals who perhaps became my unwitting accomplices. I remember being asked at our first home visit how much time I would have free to work with Sara. I answered by saying "whatever it takes." Then I asked how much time would be enough. The answer came back "more is better." In retrospect, the pattern began with that answer. **If more was always better, how could I ever do enough?**

When I ran three home programs successfully, (doing 10 trials a day, seven days a week, taking copious data on each one) then my trainer added two more programs. I probably asked for more. I really don't remember. I do know that I wish that someone had stopped me at that point, had said "enough, already!" I wish someone had pointed out to me how much incidental/naturalistic teaching I was doing every day, had pointed out just how valuable that kind of teaching is. Had I the chance to do it over again, I would never touch a data sheet. I would teach Sara as I have my other kids, incidentally, all day long, intuitively. I firmly believe from my reading and my experience that kids, be they normal or not, learn best incidentally; that kind of knowledge is the easiest acquired and the best generalized. Data based instruction has its place -- I know how valuable it can be -- but its place is not in my home on my dining room table.

I do not regret the time I spent teaching Sara in those early years. She has progressed wonderfully--she's bright, she is sensitive and I love her in ways most people never experience loving anyone. I am fortunate to be her mom. But, I do regret the time away from my husband, my other kids, myself. It was pressure I put on myself. Perhaps it was my way of coping with an unknown future. I would never do it that way again.

By the way, Sara's home trainer was, and still is my friend. She did many wonderful things that anyone who is working in this field should do. Many times she was the only ADULT PERSON that I had to talk to during the day. I relished her weekly visits. I

depended on her expertise. She always took time to listen to me. She was NEVER in a hurry to be somewhere else. She often spent the two plus hours talking to me instead of working with Sara, and never once gave me the idea it was time wasted. She helped us sort out priorities and run the gauntlet of professionals we would need to even keep Sara alive for the first two years. She helped me to see what had to be done today, what could wait a week, what could be put off indefinitely. She helped me regain a sense of control over my life. I will always owe her far more than I could ever repay. There is supreme irony in the job she does, because if she does it well, her families no longer need her: **family empowerment at its optimal result.**

How good it feels to not need her any longer, to have some sense of normalcy in our lives, and to know that we are not alone in our quest to help Sara be the best that she can be.

THE RISK OF DIVORCE: WHAT PARENTS CAN DO TO HELP THEMSELVES

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1. BE AWARE OF THE RISK TO YOUR MARRIAGE. Parents of children with handicaps are at great statistical risk for marital stress, separation and divorce. Watch out for the common problems: lack of quality communication, lack of time spent together, apathy, exhaustion, and loss of commitment to overall family welfare.

2. MAKE TIME TO BE TOGETHER, UNINTERRUPTED AND ALONE. How much time you need depends on you, but, usually several hours each week are necessary. Use available respite services, and when the respite money runs out, bite the bullet, and make child care money a priority budget item.

3. MAKE SURE EACH PARTNER IS GETTING ADEQUATE REST AND SOME TIME TO THEMSELVES. People who are exhausted cannot be good decision makers. You are more likely to have a "fight" if either one of you is always tired.

4. SHARE YOU FEELINGS ABOUT YOUR CHILD WITH YOUR SPOUSE. Frustration, triumph, and even agony are easier to bear when you have someone sharing them. When you carry the burden of those feelings alone, it causes resentment, bitterness, and anger that can eventually destroy your relationship.

5. USE ALL THE SUPPORT SYSTEMS YOU CAN FIND. Resources, both formal and informal, are in place to help families survive the stress of parenting a child with handicaps. Parent support groups can work wonders. Marriage counseling can enrich, or even save a marriage. Use respite. **NEVER** turn down a family member or friend who offers help. Tell them what you need. **ALWAYS REMEMBER THAT YOU HAVE THE RIGHT TO ASK FOR HELP. YOU DON'T HAVE TO DO THIS ALONE.**

6. SIMPLIFY YOUR LIFE AS MUCH AS YOU CAN. If that means giving up one therapy session a week for your child, or using your family and friends for support, do it. It may mean your survival. Try to schedule one day a week when you and your family don't have to go anywhere or do anything if you don't want to.

7. KEEP IN MIND THAT THE NEEDS OF YOU CHILD WILL SOMETIMES BE OVERWHELMING. All the support services in the world cannot change the fact of your child's disability, but they can be used to help you mesh your child's needs with those of everyone else in the family. Your survival as a family is the goal, and with that in mind, structure your lifestyle to meet not exclusively the needs of your child with disabilities, but the needs of all of you.

8. CONSERVE YOUR STRENGTH AND SET PRIORITIES. There is a time to fight for what you know is right for your child, and a time to back away from the battle. Don't feel you have to fight every battle to the finish. Sometimes compromise is the best way to alleviate stress. Save yourself for the battles that count most.

9. KNOW THAT YOU HAVE A CHOICE. You may need to totally alter your life's dreams and plans, and restructure your life around your child for a time (sometimes a very long time). But, eventually, most families can find ways to go on with those dreams and plans, making modifications to allow for their child's presence, but not letting their dreams die along the way. Persistence and tenacity go a long way toward finding solutions to what seem to be insolvable problems. **PERSIST AND BE TENACIOUS.**

10. KNOW THAT YOU ARE NOT ALONE. Although most parents will never know the heartbreak of parenting a child whom many in society see as "less than perfect," there are many who walk in your shoes each day. Take strength in knowing that the world is a much better place today for our children and our families than it was even ten years ago.

WHEN I FELT REALLY BAD, I READ A BOOK...

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*Most people live, whether physically, intellectually or morally, in a very restricted circle of their potential being. They make use of a very small portion of their possible consciousness, and of their soul's resources in general, much like a man who, out of his whole bodily organism, should get into a habit of using and moving only his little finger. Great emergencies and crises show us how much greater our vital resources are than we had supposed.

William James

*That which does not kill us makes us stronger.

Nietzche

*He who learns must suffer. And even in our sleep, pain that cannot forget falls drop by drop upon the heart, and in our own despair, against our will, comes wisdom to us.....

Anonymous

*Our purpose in life is not to be happy. The purpose of life is to matter, to be productive, to have it make some difference that you live at all. Happiness, in the ancient, noble verse means self-fulfillment and is given to those who use to the fullest whatever talents God or luck or fate bestowed upon them.

Authur H. Prince

*If he could speak to us he would say, "Love me with smiles and laughter...if you can only love me with tears do not bother to love me at all."

Parent of a child with severe and multiple handicaps

*Please remember that it is not always easy for others when suddenly confronted by what is to us both familiar and dear. Who can tell what people must overcome inside themselves before they can love a child for only what she is?

T. DeVries (in the book The Story of Jan)

*"Can't she ever get better?" a little girl asked me in the park one day. "No, that's not possible," I replied. "But I think that's awful," she cried out with tears in her eyes. "Yes, so do I," I agreed, "but look at her. You and I can be unhappy about it, but she's very happy. She laughs and enjoys life. Come, let's join her."

A conversation in the park

*People are always blaming their circumstances for what they are. I don't believe in circumstances. The people who get on in this world are the people who get up and look for the circumstances they want, and if they can't find them, make them.

George Bernard Shaw

*He who has a why to live can bear almost any how.

Nietzche

*Life does not cease to be funny when people die any more than it ceases to be serious when people laugh.

George Bernard Shaw

*You gain strength, courage and confidence by every experience in which you really stop to look fear in the face. You are able to say to yourself, "I lived through this horror. I can take the next thing that comes along." You must do the thing you think you cannot do.

Eleanor Roosevelt

*Healing is matter of time, but it is sometime also a matter of seizing opportunity.

Hippocrates

*Destiny is not a matter of chance, it is a matter of choice; it is not a thing to be waited for, it is a thing to be achieved.

William Jennings Bryan

*There are two ways of spreading the light: to be the candle or the mirror that reflects it.

Edith Wharton

*You see things; and you say, "Why?" But I dream of things that never were; and I say "Why not?"

George Bernard Shaw

*We are wide-eyed in contemplating the possibility that life may exist elsewhere in the universe, but we wear blinders when contemplating the possibilities of life on earth.

Norman Cousins

*Don't walk away from negative people: run!

Anonymous

WELCOME TO HOLLAND

Emily Perl Kingsley

"I am often asked to describe the experience of raising a child with a disability - to try to help people understand it, to imagine how it would feel. It's like this...

"When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guidebooks and make wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

"After months of eager anticipation, the day finally arrives. You pack you bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"HOLLAND?!?" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.

"But there's been a change in the flight plan. They've landed in Holland and there you must stay.

"The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

"So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

"It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips. Holland even has Rembrandts.

"But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of you life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

"And the pain of that will never, ever, ever go away, because the loss of that dream is a very significant loss.

"But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland."

SKYRIDING
Jan Spiegle-Mariska

Soaring higher and higher toward
The neighbors trees
Skyriding on a scooter that
Two weeks ago
She was afraid to sit on.
When did she conquer it?
Getting off, she pushes, watches,
Does it again.
Chagrinned,
I realize what I thought was
"REPETITIVE STIMULATION"
Was actually problem solving,
Experimentation.

To share
She runs inside
Persuading
Cajoling her little sister to
"WATCH ME OUTSIDE"
Soaring, both sides of the scooter
Full
With giggles and screeches and
Wind blown hair.
Teaches pumping and "be carefuls"
Likes the big sister role
Denied in so many ways
How good it must now feel.

Spring greens and grows
Unsteady at first
Like her
Fits and starts
Cold and warm
Undecided
Then, progress.
Plateau.
Inevitable, they say.
I think not.

SUGGESTED READINGS FOR PROFESSIONALS AND FAMILIES SEEKING TO FORM EFFECTIVE PARTNERSHIPS

Jan Mariska
CO-TEACH Preschool Program
Division of Educational Research and Service
University of Montana
Missoula, MT 59812

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FAMILIES AND DISABILITY NEWSLETTER, Ann and Rutherford Turnbull, editors, Beach Center on Families and Disabilities, University of Kansas, Bureau of Child Research, 4138 Haworth Hall, Lawrence, KS, 66045.

EARLY CHILDHOOD UPDATE, Susan M. Thornton, editor, University of Colorado, Health Sciences Center, 4200 E. Ninth Ave., C223, Denver, CO, 80262.

P.L.U.K. News, Katharin Kelker, editor, published by "Parents, Let's Unite for Kids," Montana Center for Handicapped Children, Billings, MT 59101-0298.

CO-TEACH

Acceptance is only the first battle

HOW SOME PARENTS OF YOUNG HANDICAPPED CHILDREN HAVE COPED WITH COMMON PROBLEMS

by

Susan Duffy, Kathy McGlynn, Jan Mariska, Jeannie Murphy

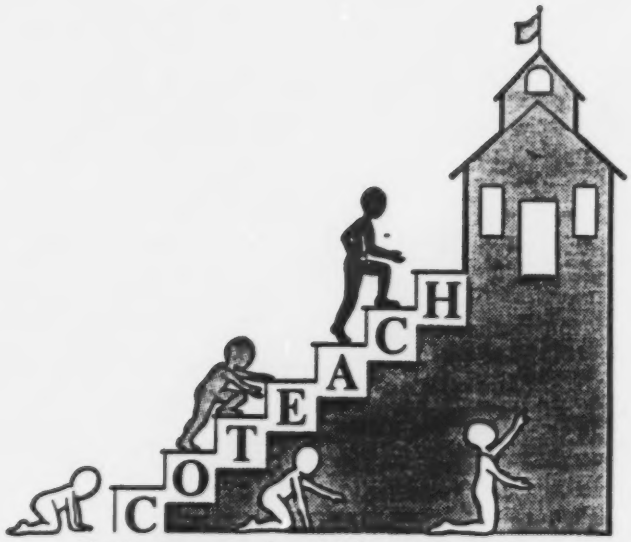
BEST COPY AVAILABLE

ACCEPTANCE IS ONLY THE FIRST BATTLE:

How some parents of young handicapped children
have coped with common problems
By

Susan Duffy
Kathy McGlynn
Jan Mariska
Jeannie Murphy

Booklet prepared by Susan Duffy, Dana McMurray, Joyce O'Neil



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This booklet is dedicated:

To our kids, the regulars and the irregulars:
Jessie, Jamie, Sara, Joel, Sean, Brendan, Michelle, Ryan, Melissa, and Keough.

To our husbands, who have backed us all the way:
Bud, Fred, Jim, and Patrick.

To friends and professionals who came through when it counted: if we named them all, it would fill the page.

To all the other families who belong to the club.

To those families who will join up later -- all our best hopes are with you.

We would also like to thank the National Information Center for Handicapped Children and Youth for allowing us to include some of their material on parent support groups.

PREFACE

The authors of the articles in this booklet are all mothers of young handicapped children who live in Missoula, Montana. Two of the women have a child born with Down's syndrome, one has a child with cerebral palsy, and one has a child with a rare form of epilepsy.

Jeannie, Kathy, and I first met in 1981 when another parent convinced the local YWCA to offer part of its space twice a month for a parent support group meeting. It is fair to say that while each of us was somewhat leery of walking into a group of unknown people, each of us felt a need for some kind of non-professionally oriented communication about our children and our lives in regard to our children.

We have been meeting ever since. We have discussed everything under the sun, it seems -- from how to get a disinterested youngster to want to crawl (a dirty ashtray set two or three feet beyond reach worked like a charm for my daughter), to handling a non-handicapped sibling's craving for attention, to methods of dealing with slow or recalcitrant insurance companies, to where one can find a liquor store in Salt Lake City if one's child is there for surgery. No subject has been too large or too trivial for attention. We have found in most instances that if something is bothering one of us, it is also bothering the rest of us or has in the past. Sometimes we've even found solutions.

In the fall of 1982, after a year and a half of meeting at the Y, several of us started a campaign to convince the school board to reinstate its preschool for handicapped children, dropped two years before in the wake of federal cutbacks to education. We were told by professionals in the field of handicapped services, by school administrators, by school board members and by others in the community that we were fighting a lost cause, beating a dead horse.

Yet in September of 1983, the preschool reopened on a half-time basis, voted in unanimously by the school board. Even more miraculously, it was funded in the main by money collected through the local school mill levy -- the first time that levy had ever funded direct services to handicapped children of any age in our town. In the fall of 1984, with no further prodding by parents, the board decided to expand the program to two half-day sessions.

This was possible because parents, board members, and administrators came to trust each other and see each other as more alike than different -- each of us with needs and each of us with responsibilities. But what made the beginning possible was the trust established over a period of time among the parents in the support group. There was incredible tolerance for missed meetings, delays and snafus because each of us knew the problems the others faced. We all had similar problems. We bouyed each other up and calmed each other down.

As August 1983 approached and a final decision still had not been made on the preschool, we met Jan. She had been following the issue's progress in the newspaper and had just given birth to Sara, who has Down's syndrome. We cried with her for her lost hopes and then said, "Well, welcome to the club." Sara was only one month old at the time. Jan and her husband, our only regularly attending father, have said that being able to walk into an already functioning group was a big help.

In April of 1984 we mothers went to the Fifth Annual Montana Symposium on Early Education and the Exceptional Child, held in Billings, to present a parent panel on subjects we had heard come up time and time again during support group meetings. We felt many, if not most, parents of handicapped children run into these problems at some point, but we had heard little discussion of the topics from a parent's point of view. The subjects included:

-- difficulties parents have in being accepted as reliable observers by many members of the medical and service-provider communities.

-- a parental need for support groups, but a lack of knowledge as to how to get one going or where to find an existing group.

-- reasonable ways for parents to choose among or resolve conflicting professional advice about one's child.

-- ways of politically affecting the community in regard to instituting or continuing services needed by one's child.

We were surprised and pleased by the enthusiastic reception we received. We were asked to make a similar presentation to an interdisciplinary group of university students and have now been asked to put our discussions into printed form. We particularly hope some of this will be useful to parents who are just beginning their long, tough membership in "the club." (Sorry you're here, but welcome.)

You know, we had a great time in Billings and, to be honest with you, the best part of the whole trip was that it gave us almost three days off from our normal responsibilities. I don't think we stopped talking for more than 30 seconds at a stretch the whole time. So, when you're reading along and thinking about how very serious this all is, envision us packed into a station wagon on the road to and from Billings with coffee thermoses and jelly doughnuts and pillows and blankets and paperback novels and (unbelievable!) no kids, and talking away and laughing our fool heads off.

Susan

Note: The final two pieces in this collection were originally written for the monograph series published by the Rural Outreach Network, based in Macomb, Illinois, and incorporate two other themes often voiced by parents: how do I survive this, and why do I sometimes feel tension when I'm dealing with people who really <u>are</u> here to help me.

Becoming a Detective in the Medical Community

Kathy McGlynn

What I have to say about becoming a detective in the medical community is based upon my own experiences with my son, Sean, who is now 8. After giving you a short history of our situation, I would like to offer some suggestions for the consideration of others who may be facing similar frustrations.

Sean is our middle son and was born with a peculiar sleep disturbance. The problem consisted of repeated, loud crying and terrifying screaming outbursts which lasted anywhere from a few minutes to several hours at a time, and occurred during naps as well as each night. At times it was so horrible that it sounded as though he was undergoing some kind of surgery without anesthetic.

We tried everything we could think of to comfort him, but nothing worked. We were puzzled that he always seemed fine when he woke up and never appeared to be afraid of going to bed. Our pediatrician recommended neurological testing, which revealed nothing, and experiments with drugs brought little relief.

By the time Sean was 18 months old his violent, nightly screaming had created a life-threatening situation. I didn't know which would come first: my death through exhaustion, or his--through my deteriorating abilities to care for an infant. I sat like a zombie--with reflexes to match. I couldn't think straight. I couldn't concentrate on anything. My body was shutting down. With no relief in sight to counter the increasing physical, emotional, and spiritual exhaustion it wasn't long before panic and despair rushed through me. We were caught in a downward spiral that was certain to do us in as individuals, a family, or both.

Our frustrations through all this were maddening. Given the absence of any clinical evidence and the doctors' lack of acquaintance with the problem, I became increasingly worried that the doctors either couldn't believe me or thought I must be exaggerating -- or had me pegged as, God forbid, a neurotic mother. Indeed, the whole scene had the makings of a good psychological horror film.

Our pediatrician suggested we seek more sophisticated testing than was available locally, so we traveled to Seattle, confident that at last the matter would be brought out into the open, diagnosed, and laid to rest. Instead, the same EEG and neurological testing was performed, the same negative findings were obtained, and the problem was summarily dismissed as behavioral.

It is important to note the fallacy in this thinking: a lack of EEG evidence of seizure activity does not necessarily mean that no seizure disorder exists -- unless we make the untenable assumption that all EEG testing is exhaustive and perfect. Unfortunately, our concerns about this were not taken seriously enough.

We were subsequently advised to seek psychological help in the area of behavior modification. Before Sean was 2, we consulted two psychologists, both of whom asked how on earth we intended to modify our son's disturbing behavior when he wasn't even awake when it happened. Despite our explanations of what we'd been told previously, both psychologists believed that the problem was neurological. Back to square one -- and the screams. What would it take to shut this kid up?

Our frustration was relieved when we finally found two anti-convulsants that, in stiff enough doses, eventually stopped the crying. But the question of why it had happened at all continued to nag at me. In spite of Sean's repeatedly normal test results, a diagnosis of seizures seemed the most plausible at this point. At age 5, we were sent to the Mayo Clinic in hopes of settling the issue. Here he was diagnosed as having not seizures but rather night terrors. The condition was described to us as a neurological disturbance of sleep from which the person cannot be aroused. Sean was taken off his two anticonvulsants (the only drugs that had worked so far) and placed on sedatives which, much to our collective dismay, had no effect.

We were again back to square one, but by then I had had it and was determined to find out what was going on.

We resolved our mystery with a little detective work and a lot of luck. Based on our experiences, I would now like to discuss some practical ways to doing what you can to help figure out a baffling problem you may be having with your child.

1. <u>Be specific about the problem</u>. As the early months passed, we became convinced that Sean's brand of crying was not normal and that explanations for it that were given to us did not make sense. For example, we did not believe that Sean's behavior was, as one neurologist put it, just a phase our son was going through. I found myself saying, "I believe my son is crying for a reason. I want to know what the problem is, why he's got it, and what to do about it." It is important to trust your own instincts. You know your child better than anyone else.

2. Know what you're talking about. In addition to your own notes, keep daily, written records that list specifics desired by people whose opinions you trust. For example, one doctor told me, "I want to know the length, frequency and intensity of these crying spells. You put one eye on the kid and the other eye on the clock." By doing this we could then report, for example, "We had 25 outbursts last night, the first starting at 10:30. They lasted anywhere from five minutes to an hour and a half." The records enabled us to look for patterns in Sean's sleep behavior but, unfortunately, there didn't seem to be any.

3. Keep talking to people -- eventually you may get a number of viable leads. Nobody we knew had a problem like ours, but we were able to move closer to an answer by following up on others' remarks. For example, a woman I worked with had a son in paramedic training in Seattle. I never met him, but he took it upon himself to ask the neurologist he worked with about Sean. That doctor said, "That's nocturnal epilepsy, and the only way you can deal with it is with drugs. Since the problem has been present since birth, it can't possibly be behavioral."

4. Research the problem on your own. Doctors frequently have neither the time nor the impetus to delve into your particular problem. I went to the library and started looking up terms and drug names I'd latched onto. I soon located an article that dealt with the potential significance of unusual nocturnal problems in the first decade of life. (The article, by the way, had been printed 11 years before and someone among the many specialists who saw Sean should have been aware of it.) The senior author of that article subsequently diagnosed Sean -- by mail, no less! Other research possibilities include scanning letters from other parents in the Readers' Forum of Exceptional Parent magazine and doing a computer search using likely terms or names. And there is always interlibrary loan. Don't be afraid of the technical stuff -- it's not that hard to decipher.

5. Consider what you're told in relation to what you've observed. For example, we were told that Sean was a behavior problem. Okay, then why wasn't he afraid of going to bed? Why did he deny having bad dreams? Why was he never aware of his violence come morning? Why was he so good-natured and enthusiastic during the day? This explanation for our little Jekyll and Hyde just didn't make sense. Do not downplay your observations -- they can be the central clue to the mystery.

6. Think it through. If the doctors say they can't find anything organically wrong and the psychologists can't find any social or emotional factors to explain the behavior, then what else is there? Demonic possession? I actually had one person tell me to take my son to an exorcist, and she wasn't joking.

7. Find the right specialist. You have to find a doctor who believes you are a rational, observant person and that credence can be placed in what you say. Things to consider: Is he really giving you his undivided attention? Is he interested in what you're seeing and finding? Does he understand the family dynamics involved? Keep going until you find this person. If he doesn't know very much about your particular problem, ask him what he plans to do to find out. Remember, even the experts can be wrong. This pursuit is not "doctor-hopping." It is a legitimate search for an answer. A support group can give you leads here, even if no one in it has a problem like yours.

8. Check out other professionals. I got all kinds of leads and assistance from our pharmacist. He recognized my frustration and immediately offered to help. He willingly answered my endless questions about the drugs we were trying, obtained additional information for me whenever I needed it, and helped steer us in the right direction. In the absence of any hard data other than our nightly record, which by then showed improvement in response to drugs, he was one of the first to support our eventual diagnosis of temporal-lobe seizures -- rare in children, but nonetheless real.

Systematic pursuit should help you find what you need. Don't give up although it may take far more time than expected before you are satisfied. Although anticonvulsants had stopped Sean's crying and screaming by age 3, it took six years for us to pin down exactly what was going on. I continued my search because I kept wondering if we were drugging Sean for his own benefit or for mine.

In any event, take the bull by the horns. Leave no stone unturned. Keep asking questions until it all makes sense. Good luck!

Suggestions for Being a Detective

1. Be specific about the problem.
2. Know what you're talking about.
   - -- Keep daily, written records that list the specifics desired by people whose opinions you trust.
   - -- Look for patterns of behavior and response.
   - -- Note anything that strikes you as relevant.
3. Keep talking to people until you get some viable leads.
4. Research the problem on your own.
   - -- Search the library's available books and references.
   - -- Scan the Readers' Forum of Exceptional Parent magazine.
   - -- Investigate computer searches.
   - -- Utilize interlibrary loan.
5. Consider what you're told in relation to what you've observed.
6. Think it through.
7. Find the right specialist.
   - -- Go for additional opinions.
   - -- Try a support group for names and leads.
   - -- Make inquiries of people who have similar problems.
   - -- Contact your local medical board.
8. Check out other professionals:
   - -- Pharmacists.
   - -- Nurses.
   - -- Psychologists.
   - -- Teachers.

Finding and Founding Support Groups

Jan Mariska

I'm going to talk to you about support groups, but before I do that, I want to talk about isolation. Isolation, for our purposes, can be defined as being the Mom or Dad of a handicapped child in a world of "normal" families. Put simply, it is the feeling of being different and alone -- the feeling that you are the only one that has your problem.

When my third daughter, Sara, was born with Down's syndrome, isolation is what I felt. I had what seems to have been a unique experience in that I was surrounded with supportive people at the time of Sara's birth and diagnosis. The medical people who dealt with us were very sensitive; my husband and close family were incredibly helpful; our friends were trying desperately to understand what had happened. Yet, through the first few weeks I felt isolated -- almost as if I were insulated from the very people who were trying to reach me the hardest. In those first agonizing days, I felt desperately that no one, absolutely no one, knew what I was going through.

In a year's time, a lot has changed. If people had told me a year ago that today I would be part of a panel presentation on handicapped kids, I would have laughed in their faces. The changes in my life have happened primarily, of course, because of Sara. But in a large part they have happened because of a group of people I met through the local YWCA in Missoula. I belong to a support group for parents of handicapped children, and to say they have helped me is to make the understatement of the year. To be with them is to no longer feel isolated.

I chose to talk today about finding and founding support groups because, when I look back on the last year and pick the one thing that allowed me to hold myself together, it would have to be the people in that group.

Our group does not intend or pretend to replace physicians, therapists, or other professionals. We function in the belief that many of our needs go beyond the bounds of formal service measures. What we can offer each other is uniquely ours, because we all have paid our dues. We all have "been there," and we all know how it feels to have a child who is way less than perfect.

To people who live with exceptional children, the problems associated with just getting through one more day can be overwhelming. We have all the problems and obligations that ordinary families have, plus. Our situation is, at the very least, different. Talking to other people who have had days much like your own provides an emotional outlet that, at least in my experience, cannot be found anywhere else.

Talking with anyone helps, but talking with another person who actually understands is invaluable. All of us have had a best friend -- someone who accepted what we had to say at face value, who understood our dreams and disappointments, who tried to help us over the rough spots. That is what the people in our group are to me. If I didn't have them, I'd be okay but I can honestly say that I know I am coping much better with their help than I would have without it.

After doing some research on support groups, I have found there is no such thing as a "typical" group. They can be very informally run, much as ours is -- just a group of people to share their common concerns over coffee. They can be formally run by advisory committees and salaried program coordinators. Some groups organize around one specific handicap, but most open their membership to families whose children's problems include a whole range of handicaps. In rural areas some groups even meet by mail, coming together to share their feelings face to face only infrequently. The great thing about support groups is that their members can structure them to fit their own needs.

However they are structured, the groups all seem to share some common functions. First and foremost, they offer mutual support by lessening the isolation that people with special kids often feel. They provide a place to go where you can say what you're thinking and be understood. Research scientists, incidentally, have found a strong link between the strength of our social support systems and our mental health. Such support clearly influences our ability to handle the stressful events in our lives.

Second, support groups provide a forum for the beginnings of advocacy. Parents who act together are much more likely to have their needs heard and acted upon by the powers that be. It was a group of parents who began what is now the National Association for Retarded Citizens; it was a group of parents who founded the March of Dimes; it was a group of parents who started the Easter Seal Campaign. Kitchen-table politics can and does accomplish miracles. It was a group of parents in Missoula who convinced our school district to reinstate a preschool program for handicapped children that had been dropped. And, it is a group of parents who will go to the next session of the Montana Legislature to propose that such preschools be mandated statewide.

Third, support groups allow parents to share valuable information and ideas on everything from who the best pediatrician in town is for our kids, to where to find diapers that fit a 5-year-old kid.

Fourth, a group allows its members access to professionals in the community from whom they might not otherwise have been able to gain information. Because many members of our group have children with genetically based problems but may wish to have further children, there is a great deal of interest in amniocentesis. Although none of us on our own would have asked our obstetricians to spend two hours discussing amniocentesis with us, as a group we were able to ask in an obstetrician who did spend that much time with us. And in the group setting we felt secure enough to ask all the questions we wanted answers to.

So, how do you go about finding out whether a support group exists in your area? If you are working with an early intervention team, they should know if such a group exists. The Comprehensive Development Center in Missoula routinely makes referrals to our group. You can ask your doctor or call the local AMA. You can contact the county health nurse. You can call local organizations who are likely to sponsor such groups, such as ARC or the Easter Seal Society. Special-education teachers or the local PTA may be of help. Many larger support organizations are listed in the Yellow Pages under "psychology." Local newspapers often carry bulletins of upcoming meetings; scan them for mention of a support group. You can also write to the state Special Services Office or to the Office of Public Instruction. If you strike out in all those areas, it's probable that no group exists -- so start your own!

You can start your own group by finding one other parent with similar concerns. Things can get sticky here because, with the law governing patient/professional privacy, a professional (who is the most likely person to know of someone else in your situation) cannot give you the name of that person. The law, however, can be circumvented if you give the professional your name and telephone number and ask her/him to pass on that information to other people in your area with similar problems.

To contact people nationwide, you can write to publications for parents and professionals that carry a letters column. The Exceptional Parent magazine has been an invaluable tool used by members of our group to reach other parents with similar specific problems. There are also three national organizations in existence whose specific goal is to match parents through the mail. They are listed on one of the handouts. One of them, Pilot Parents, will provide a kit to help you get started with your own group.

SOME THINGS TO REMEMBER THAT HAVE WORKED WELL FOR OUR GROUP

1. We try always to keep in mind that no problem with a child is small. Some handicaps are temporary or less severe than others, but to the parents who are dealing with that problem it is the biggest thing they have ever had to face. We strive for sensitivity to everyone's needs.

2. Making personal contact with other parents is the best way to get them to come to your group. If you can, CALL THEM and invite them. If it seems less threatening, have someone in the group meet with them one-on-one before asking them to face a group. Provide transportation, especially the first time they come to a meeting. See about carpooling later on.

3. Our group welcomes children at our meetings simply because a lot of us could not get there if we had to get sitters. Their laughter and screams permeate our meetings much as they permeate our lives.

4. We have tried to be as unrestrictive as possible. We discuss all kinds of handicaps. We welcome fathers as well as mothers, single parents as well as couples. The more people who come, the more we all seem to benefit, the more our problems are put into perspective, the more we realize how well we actually are coping and how much insight we have gained.

5. We have been happier running our group ourselves with very little professional help. We sometimes invite professionals in to speak or to listen and we are told by them that they have grown much in their understanding of our needs simply by listening to us.

6. Meet on neutral ground if you can. It is somehow much less threatening to go to a meeting room in a building than to walk into a stranger's home. Most civic organizations have rooms available for such purposes and, if nothing else is possible, even a restaurant is preferrable to a private home.

7. It may help to know that we do a lot more laughing together than crying. Although we often come in the door frustrated, angry, bitter and feeling helpless, we rarely leave that way. Support group is generally not a place where people come and fall apart at the seams . If and when that does occur, we can almost always patch the seams to hold for another couple of weeks.

8. Some of our husbands are leery of what goes on at these meetings. We do have a few who come, for those who make it through the door once almost always come back again. We keep encouraging them. If it's a hopeless cause, we simply say, "You have your night out with the boys, and I have support group." In very many ways they serve the same purpose.

In summary, I would like to note that these people and the ones back in Missoula who did not come with us today have shared my worst agonies, but more often they have celebrated with me my happiest moments. They have shared with me those little victories that to our children are not so tiny. At our last meeting we celebrated Sara's first birthday. In ways that very few people will ever understand, it was a celebration of life itself, and of the fact that none of us need ever be isolated again.

National Information Center for Handicapped Children and Youth
Box 1492
Washington, D.C. 20013

WHERE TO GET IN TOUCH

Three parent groups that were started at the grassroots level and now have many local chapters are Parentele, Pilot Parents, and the National Parent CHAIN. Each of them involves parents of children with any type and severity of handicap.

Parentele: An Alliance of Parents and Friends Networking for Those With Special Needs

Parentele grew out of parents' needs to communicate with each other and work together to meet the needs of their sons and daughters. The organization has representatives in each state, and its Board has adopted these statements of their philosophy:

- We believe that persons with handicaps are valued, developing human beings with the potential to grow and contribute to society;
- We believe that parents are the key to developing these potentials;
- We believe exchange of information provides support and assistance to parents;
- We believe in parents' promotion, advocacy, and monitoring efforts;
- We believe the expertise unique to parents makes a valuable contribution;
- We believe in a national linkage to strengthen and encourage parents.

For more information, write to: Patricia Koerber, 1301 East 38th Street, Indianapolis, IN 46205; or Elaine Clearfield, 310 South Jersey Street, Denver, CO 80224.

Pilot Parents

A group of parents of mentally retarded children started Pilot Parents in Omaha, Nebraska, in 1971. In 1974 the organization expanded to include parents of children with any handicap. Pilot Parents groups train parents to help other parents of handicapped children in times of special need, such as at initial diagnosis. For more information on finding or starting a Pilot Parents group in your area, contact Keryn Paul, Omaha Association for Retarded Citizens, 3610 Dodge, Omaha, NE 68131.

National Parent CHAIN: Coalition of Handicapped Americans Information Network

National Parent CHAIN is a recent effort to unite parent and parent/professional groups across the country. Its major goals are:

- To link existing parent coalitions, alliances, and other groups for information sharing purposes;
- To disseminate timely information electronically;
- To serve as a communications link between the States and the Federal government; and
- To affect State and public policy regarding the handicapped.

For more information, write to: National Parent CHAIN, 515 West Giles Lane, Peoria, IL 61614.

Specific Disability Groups

The National Information Center for Handicapped Children and Youth has information about national organizations and other parent groups. The addresses of national organizations are listed on the Fact Sheets on Specific Handicaps. State chapters of many organizations are shown on the accompanying State Sheets. The State offices have information about chapters even closer to you, which you can obtain by writing or calling them. The National Information Center for Handicapped Children and Youth has information about parent groups that serve parents of children with rare syndromes and also unaffiliated local parent support groups. For these names and addresses, contact us directly at

Post Office Box 1492, Washington, DC 20013.

Federally Supported Parent Programs

The Division of Personnel Preparation, Special Education Programs has addressed the training of parents for a number of years. By 1980, 10 projects were funded to begin a network of parent coalitions. A coalition is described as one "made up of a broad spectrum of parent groups proposing to attend to the training of parents in the rights they and their handicapped children have under Public Law 94-142, and the ways they can exercise those rights in ensuring that their children receive a free, appropriate public education. The intent of the training is not adversarial, but a trained, knowledgeable group that works with the schools and other related service agencies to ensure appropriate programming for handicapped children." Currently, 31 parent projects are supported. They are:

Team of Advocates for Special Kids
1800 East Laveta
Orange, CA 92666
Director: Jean Turner

Georgia Association for
Retarded Citizens
1851 Ram Runway
Suite 104
College Park, GA 30337
Director: Mildred J. Hill

La Grange Area Department of
Special Education
1301 West Crossit Avenue
La Grange, IL 60525
Director: David W. Peterson

Task Force on Education for
the Handicapped
812 East Jefferson Boulevard
South Bend, IN 46617
Director: Klemens S. Bartosik

D.C. General Hospital
Department of Pediatrics
19th & Massachusetts Avenue, S.E.
Washington, DC 20003
Director: E. Elaine Vowels

Designs for Change
220 South State Street
Suite 1616
Chicago, IL 60604
Director: Donald R. Moore

Coordinating Council for
Handicapped Children
220 South State Street
Chicago, IL 60604
Director: Charlotte Des Jardins

Southern Illinois University
Department of Special Education
Carbondale, IL 62901
Directors: Priscilla Presley and
Norma Ewing

Federation for Children with
Special Needs
312 Stuart Street, 2nd Floor
Boston, MA 02116
Director: Martha Ziegler

New Hampshire Coalition for
Handicapped Citizens, Inc.
P.O. Box 1422
Parent Information Center
Concord, NH 03301
Director: Judith Raskin

Lehman College
CUNY Research Foundation/H.H.
Bedford Park Boulevard West
Bronx, NY 10468
Director: Brian Hurwitz

Appalachian State University
Human Development Research
Institute
Western Carolina Center
Morgantown, NC 28655
Director: Max Thompson

Ohio State University Research
Foundation
National Center for Research
in Vocational Education
1960 Kenny Road
Columbus, OH 43210
Director: Martin Richards

Western Oregon State College
Special Education
345 North Monmouth Avenue
Monmouth, OR 97361
Director: Thomas D. Rowland

Resources for Human Development Inc.
Action Alliance of Parents/Deaf
120 West Lancaster Avenue
Ardmore, PA 19003
Director: Roberta Thomas

Association de Padres Pro
Brenstar de Ninos Impedidos
de Puerto Rico, Inc. (APNI)
P.O. Box 21301
Rio Piedras, PR 00928
Director: Carmen Selles

PACER (Parent Advocacy Coalition for
Education Rights)
4701 Chicago Avenue South
Mineapolis, MN 55407
Directors: Paula Goldberg and
Marge Goldberg

Southern Nevada Association for the
Handicapped
1918 Pinto Lane
Las Vegas, NV 89106
Director: Vincent Trigg

Montclair Board of Education
22 Valley Road
Montclair, NJ 07052
Director: Stephanie Robinson

Advocates for Children, Inc.
24-16 Bridge Place South
Long Island City, NY 11101
Director: Miriam Thompson

Southwestern Ohio Coalition for
Handicapped Children
Social Information Center
3024 Burnet Avenue
Cincinnati, OH 45219
Director: Thomas Murray

University of Oregon
Center on Human Development
901 East 18th Avenue
Eugene, OR 97403
Director: Diane D. Bricker

Teaching Research
Oregon State System of Higher
Education
345 North Monmouth Avenue
Monmouth, OR 97361
Director: William Moore

IIA of World University
Barbosa Avenue Esquina
Guyama Street
Hato Rey, PR 00917
Director: John Hennig

Education Advocacy for Children
With Handicaps (EACH)
P.O. Box 120731
Nashville, TN 37212
Director: Harriet J. Derryberry

Parent Educational Advocacy
Training Center
228 South Pitt Street
Room 300
Alexandria, VA 22314
Director: Winifred Anderson

PEP Coalition (Parent Education
Project)
United Cerebral Palsy of
Southeastern Wisconsin, Inc.
Suite 434
152 West Wisconsin Avenue
Milwaukee, WI 53203
Director: Liz Irwin

West Virginia Department of
Education
Office of Special Education
Capitol Complex, Building 6
Room B-309
Charleston, WV 25305
Director: William L. Capehart

PAVE (Parents Advocating Vocational
Education)
1515 North Orchard
Tacoma, WA 98406
Director: Martha Gentill

Center of Development Disabilitites
499C Waterman Building
University of Vermont
Burlington, VT 05405
Director: Wayne L. Fox

Parent to Parent National
University Affiliated Facility
The University of Georgia
850 College Station Road
Athens, GA 30610-2399
Director: Sally B. Carter
(Funded by the Department of Health and
Human Services)

Information about Parents Helping Parents and other parent support activities is continually expanding. Please keep the National Information Center for Handicapped Children and Youth informed about activities so that the information can be shared with other parents in your area. Innovative ideas and successes need to be shared. For new parents, there is a great deal of information available. Take and use what is helpful for you. Begin an information file and keep track of ideas, etc., that may be useful later. Keep in touch.

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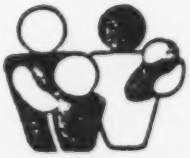

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What to Do About Conflicting Professional Advice

Jeannie Murphy

My presentation concerns conflicting professional advice concerning your handicapped child. I chose this particular subject because of my son, Ryan, a 3-1/2 year old with severe cerebral palsy. Ryan has had problems since birth, but it was on a trip to Seattle for medical advice about his seizures that we were told about his cerebral palsy. That diagnosis has led us to seek professional advice about almost every aspect of his life.

We have consulted with a wide range of professionals, including neurologists; opthalmologists; orthopedists; pediatric specialists; physical, occupational and speech therapists; hearing specialists; psychologists; neonatalists; dieticians; and school personnel. Each specialist dispensed advice. The advice has ranged from "Take him home and love him" to "Institutionalize him," and has included everything in between.

We have received advice and information about medications, various forms of therapy, orthopedic devices, glasses and surgery, classroom situations, how to handle Ryan in our home, and behavior modification. Many times we've been given medical referrals to yet another specialist. Ryan has been poked, prodded, and tested for years. We have not been "doctor hopping," it's just been the normal range of professionals one runs into when one has a special child.

Along with most consultations, we received a plan of care for Ryan. I was trained at home in areas of physical therapy and handling. Programs were designed for me to carry out with Ryan that could and sometimes did take more than two hours each day. Additionally, he received three to four hours of therapy at a rehabilitation center each week, and we also took him to the local university for students in physical therapy to "practice" on him. When I add on time spent at doctors' appointments, in travel and in endless waiting, we were spending 25 to 30 hours per week just getting Ryan to, from and through therapy -- more than half of it outside our home.

It was like holding down a full-time job with very few fringe benefits. Our two daughters were literally growing up in hospital hallways while waiting for their brother. Our so-called family vacations were spent in Seattle for on-going medical advice. Our medical bills were sky high and Ryan was not getting better. Since I was responsible for Ryan's home programs, if I skipped part or all of them for a day to spend extra time with the girls or on housework, my guilt overflowed. Were Ryan's needs going to demand more and more of us as he got older until they totally consumed us all?

Eventually we reached a point when trying to be all things to all people was impossible. Ryan was in the hospital as a result of the flu, an illness that in most children does not require such extreme measures. As I watched him lie there in the hospital bed, I began to wonder just what we were preparing him for? What had we done for Ryan so far that was doing him any good and would enable him to live a full life?

While on one of our many trips to Seattle, I had read a newspaper article about a home-therapy program that was helping kids like Ryan. I called the mother of the child in the story and received from her the courage to go on and the courage to begin our home program, which deviates from conventional approaches toward children with cerebral palsy.

It is with this conflict with traditional therapy methods that my story really begins. In the past, we received and coped with conflicting advice between and among professionals, but now we are facing a united front of professionals opposed, for the most part, to our chosen path of therapy. To get through the first 2-1/2 years and especially this last year, we have had to approach conflicting advice from professionals in a step-by-step manner.

I offer some reflections for consideration by parents in similar quandries:

1. Remember that your child's well-being is your first and foremost consideration. How does he respond to what is advised? Does he make progress? Are you being asked to do something to him or for him that could hurt him? Your own experience with your child will help you make decisions concerning his well-being. In our situation, Ryan is doing great. He is happy, alert and improving every day.

2. Your family comes next. As a group, you all have to deal with your special child. What position does particular advice put your family in? In our case, putting Ryan on a home-based program has been a blessing. We can all be home, and with the help of volunteers I can spend much more time with all <u>three</u> children. We <u>all</u> feel proud that Ryan is improving because we <u>all</u> have a part in it.

3. Emotional factors also have entered into our decision. My guilt is reduced because I now have time to care for all my children and feel I am doing the best that I can for them. I also have a more positive feeling about Ryan and his potential.

4. At times, legal factors have concerned us. You may have a "Baby Doe" and may have to make decisions that could be challenged legally.

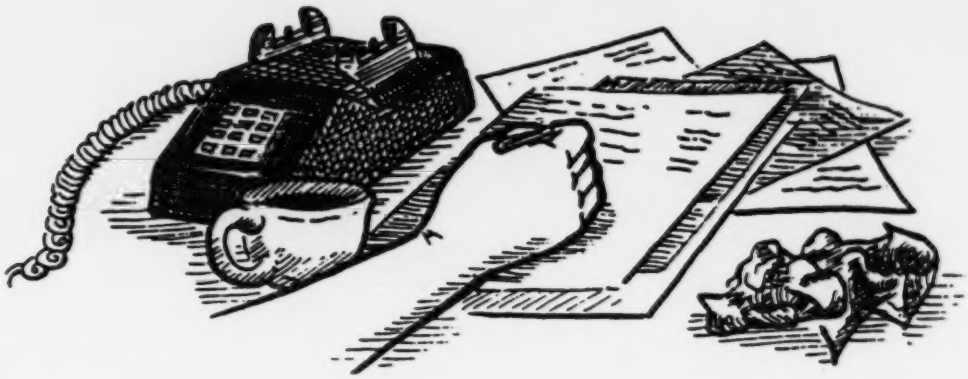
5. The economics of care and therapy are a reality to consider. We received advice ranging from simple low-cost ideas to expensive orthopedic devices and surgery. If medical bills threaten all you have, this reality must enter into your decision. Our medical bills have most certainly declined since we decided on our course of home therapy, done under the guidance of a team of experts we consult every three months during trips to Seattle. The expenses involved are far less than Ryan's former medical bills. We also feel the therapy we have chosen will cut down our expenses for adaptive equipment in the future because we are lessening Ryan's chances of needing the equipment.

6. Time is a big concern. Will what is advised be impossible for you to handle? Will there be enough time in the day to accomplish it and continue with the other responsibilities and needs in your life? We still spend 24 hours a week on Ryan's therapy, but none in travel or waiting. All 24 hours are productive.

7. Long-term goals are a final consideration. What do you hope for your child and yourself as a result of given advice? Our goal is to see Ryan function at his fullest potential. In our situation, our home program gives us the best chance of reaching that goal.

Explore the many ways to resolve conflicting advice. Seek second opinions. Educate yourself about your child's problem. Consider whether a professional's suggestion is reasonable and makes sense. Can you live with it? Talk with other parents who have gone through much the same thing. A support group in your community is a terrific resource because all of those parents have had to come to terms with conflicting advice, too. Weigh the possible alternatives and trust yourself. You know your child better than anyone who sees them once a week, month or year. You are the consumer -- don't settle for the best sales pitch and don't let lack of a decision be a decision. Decisions do not need to be made overnight. Our decision to go with our home program took more than a year.

All parents have choices to make, whether their children are well or hurt, and there will always be areas of conflict. No matter how old the children are or what they may be doing, the battle continues. When one problem is resolved, chances are another will crop us, but keeping yourself informed and aware of your situation and child is your best defense. With each decision, you lay the foundation for future decisions. Remember as you make each choice that it does not have to be permanent. One step at a time, one day at a time is enough for any of us to handle.



Being a Mom is a Political Experience

Susan Duffy

If there is anything that parents of children with handicaps learn rapidly, it is that services for our children are subject to change due to lack of money, ignorance of their necessity or the whims of those in positions of authority. Although it is a pain in the neck to continually have to reinvent the wheel and re-educate the public, it is a necessary, on-going process.

Becoming the parent of a child with handicaps is, for those reasons, one of the most rapid boosts toward assertiveness that one can receive. It becomes a matter of survival -- your own and your child's.

Three adages come to mind:

-- The squeaky wheel gets the grease.
-- You catch more flies with honey than with vinegar.
-- Don't get mad, get organized!

Saul Alinskey, a famous and unorthodox labor organizer, once said, "You don't have to have the majority of the people for you, you just have to have the majority of the people not against you." Most people are apolitical or apathetic about social causes and, for the most part, that's okay. You cannot convince everyone of the righteousness of your cause anyway. The people you have to convince are those who have the power to make the changes you want to have made.

When organizing for a cause -- new services, expansion or upgrading of existing services, etc. -- several points should be kept in mind:

1. Exactly what do you want and why? If you can't get what you want, what are you willing to settle for?

2. Who has the power to give you what you want? How do they feel about the issue? What are their reservations and why? What part of the issue, if any, do they support?

3. Has the cause been fought before? If so, by whom, when, and why did they lose?

4. What factual information supports your cause? What factual information needs to be overcome?

5. What groups beside your own have reason (you may have to think up the reason for them) to support your cause? What groups will fight it and why?

All of these questions will need to be answered before you can effectively wave your banners. Once you are fairly sure of the answers, you are ready to go public. The following suggestions are some ways of going about it.

1. Have a fact sheet to hand out that explains what you want, why you want it and why people should support it. Families of handicapped children are constantly accused of wanting more (we do, of course) and of not being grateful for what our children have already been given. (Parents of regular kids are not asked to be grateful for the existence of public schools and extracurricular activities, but that is another issue.) Your job is to show people that what helps our kids helps the community at large, too.

2. Write a letter outlining your cause, your reasoning, and your proposed solution and send copies to every community organization you can think of asking them to endorse your cause. Add a separate cover letter to each that explains why you feel that group has a personal stake in the issue. For instance, veterans' groups might have a stake because Viet Nam veterans have an unusually high rate of children born with birth defects; churches support the causes of less fortunate people in general; Planned Parenthood and Right to Life groups both promote stability in families; medical people spend a lot of time and effort keeping handicapped children alive; the Chamber of Commerce promotes community services to businesses considering relocation to their area, etc. You can usually make a connection if you think about it. Look in the Yellow Pages, find out what groups exist and write to all of them. You are <u>not</u> asking their members to go out and beat the streets for you, you are asking only for their endorsement -- but accumulated endorsements from a cross-section of the community add up to strength.

3. Figure out who the best speakers are in your group and offer their services. Most local groups have monthly meetings or luncheons and would be happy to have your speaker fill their programming slot. Just making the offer may help you in some cases.

4. Write short, reasoned letters to the editor of your newspaper. Go in and talk to the editor about your goal. He or she may be happy to write an editorial on the subject if you suggest it -- editorial writers are often stuck for topics of local interest. (Don't ask for an editorial if the writer seems hostile to your cause, of course.)

5. Most local television and radio stations have local talk shows. They may run at peculiar times, but they are free to your group. Broadcast media in Montana have just as much air time to fill as do stations in New York City, but have fewer people and causes competing for their time. Broadcast media are required by law to present a certain amount of "public service" programming and your group qualifies as such, thus helping them out, too. So go in and ask. If you will be holding a meeting, particularly if there might be good "visuals" involved, notify the television news people. They are particularly hard up for news on weekends. People who see that your cause is gaining media coverage will be likely to take you more seriously.

6. While in the process of launching your campaign publicly, make personal contact with the people who have the power to change the situation. Make these contacts by appointment so that the time you have will be uninterrupted. Because persons in authority are more comfortable on their own turf, try to arrange your meeting on neutral ground, perhaps in a restaurant over coffee. If there are several people who need to be convinced -- a school board, for example -- make your contacts individually. People in groups feel less personally responsible for what is being discussed.

7. When you meet, be prepared. Have your facts and figures ready. Know the answers to questions you are likely to be asked. Be straightforward and non-threatening. It is easier for people to agree with someone they can <u>like</u> and with whom they feel something in common. Hidden agendas and veiled threats make people nervous. Tears and shouting make people nervous and embarrassed. Be pleasant, businesslike and informed. Remember that having a child like one of ours is one of the worst things other people can imagine happening in their own lives and they are uncomfortable with their own feelings. You need to show them that as people and parents you are more alike than different. Do not play to pity. Play to logic, community responsibility and basic goodness (it's in there somewhere).

8. After you have spoken individually with the persons in authority, identify who is for you, who is against you and who is wavering. Consolidate your positive support. Do your best to resolve the problems the waverers have with your cause. Find out if your group and a waverer have any mutually respected friends and have that person speak with the waverer on your behalf. If you have a non-dramatic opportunity for the waverer to meet your child, take it. Most of our kids are doing a lot better than most people think they are, but it takes a parent to point out how well the child is doing because the public has a hard time getting past the face of the situation.

9. Keep plugging until you get what you want. It may take awhile, but you need to remain visible. It is much easier for persons in authority to ride out short campaigns than on-going efforts, especially if you are continuing to educate the public as you go along.

10. When you win, don't celebrate your victory as a battle that has been won by your group over another. Make it a celebration for the community, of a cause that everyone had a stake in but wasn't aware of until you came along. Go back and say thank you to everyone who helped you out in <u>any</u> way. Thank them personally, through letters and in the newspaper. And always remember that those filling positions of authority change from time to time and the new people will have to be re-educated. It is much easier to do this on a continuing basis than by having to launch a whole new campaign because you let something go by inaction.

Things Some Professionals Did That Drove Us Nuts And Made Us Crazy:

Parents Speak to Professionals

(We added this section at the suggestion of the university professor who invited us to speak to future professionals.)

1. Each of us at one time or another has been treated as a hysterical or neurotic mother or both. We've all known hysteria, but have been driven to it by stress (financial, emotional and physical), by the professional brush-off, by a lack of information (especially current information), by conflicting diagnoses and advice, and by real fear and concern about our children's well-being.

2. We were sometimes treated as not smart enough to grasp medical terminology, so problems were explained only in layman's terms. We need both -- the layman's terms help us understand, but the medical terms allow us to read and research on our own.

3. Our observations were sometimes disbelieved by professionals unless confirmed by our husbands or by another professional.

4. We've waited weeks and months to get specific appointments, then hours in waiting rooms, only to be given 10 minutes of brusque platitudes and what we perceived to be half-hearted attention and involvement -- often interrupted by phone calls.

5. We probably understand the nature of medical emergencies better than most people, but when we are left sitting in medical waiting rooms without any attempt to discover whether rescheduling would be a better option or whether we might have errands we could be running during the delay, we become angry and frustrated. It is difficult to transport some of our children, difficult to find babysitters for them if it is one of our other children who needs attention. And most of us work. The time we miss by sitting in waiting rooms means less money we have to pay the bills.

6. Most of us have been told that a problem our child has is "normal" and that he or she "will grow out of it." We have not found this to be the case. One of our children had a rare form of epilepsy, undiagnosed for six years. Another child would have died had the mother continued to listen to such assurances.

7. We have been left in hospitals to relay bad and/or complex news to the spouse at home, who inevitably has questions about the situation we didn't think to ask. It's an additional stress on the marriage that we don't need. Please stick around to make the telephone explanation, too.

8. We have been asked to make decisions, sometimes life-or-death decisions, on the basis of scanty or outdated information. How can one possibly make a decision for or against surgery needed to save the life of a child with Down's syndrome 20 minutes after her birth when one's only "information" is inaccurate myth?

9. Often, when the news was bad, the messenger couldn't look us in the face. We deserve at least that courtesy. We are the ones who have to cope in the long run.

10. Many professionals have been warm, sensitive and understanding only to have their empathetic work undone by an insensitive underling. Technicians, receptionists, orderlies, cafeteria servers and others involved in professional operations need to be just as aware of parents as their bosses. They see us more often and for longer periods.

11. In trying to ease our pain, professionals have sometimes tried to make less of our children's problems than was realistic. In every case, that has caused us greater pain later. This is not to say all bad news should be dished up as rapidly and bluntly as possible, rather that an honest diagnosis with all the concommitant unknown possibilities presented from one imperfect human to another is better than false hope or no hope.

12. We have been asked to consider problems that will relate to our children only far into the future. When one is having trouble getting through each new day, it is ludicrous to be asked to consider the possiblity of, for instance, future sterilization for one's one-month-old baby girl with Down's Syndrome.

13. Professionals, especially specialists, tend to look at our children with tunnel vision. It is not only the child who is at stake when diagnoses, treatment plans and transportation requirements are discussed, it is the entire family. What good is all the treatment in the world for the child if the family cracks up from financial and physical stress and the child loses the best possible environment for progressing. Too many families of handicapped children <u>do</u> split up in divorce because of the strain. In fact, the divorce statistics run at around 75 percent.

14. Some professionals, not knowing the answer to a question, have told us not to worry about the question. It is always better to say, "I don't know, but I will find out," and then do so. Of course, there are questions for which no one has an answer and it's better to say so straight out. If, as a professional, you simply lack the time to go searching for an answer, tell us where to look for you.

15. We have sometimes offered suggestions or information based on our own reading, observations or thoughts and been rejected as interfering, susceptible to quackery, searching for miracle cures or unaccepting of our children's conditions. We do sometimes bring in weird ideas, but the best way to deal with us is to explain why the idea is or is not good for our child, whether it has been proven false or is still being tested, whether it will actually harm our child to try it. We do not need false hope, but we do need hope -- and the fields of medicine and early intervation are ever-changing, sometimes from year to year. Few of us have any expectation that our children may someday be "perfect," but we work to help them become less imperfect.

16. We have been given verbal instructions or summaries when we've been in charged emotional states. Please write it down so we have them on hand later. The moment of a crisis is not the best time to offer important details.

17. Our children have been scheduled for tests at their naptimes and then we've been told they are behavior problems. Be realistic about the fact that they are children, albeit with special problems.

18. No one at the hospital asked us if we wanted a birth announcement put in the newspaper. They just assumed that we didn't.

19. Our children have special needs and consequent talents that must be considered. Nurses, don't strap down the arms of a child who communicates only with sign language. Find another way to keep that IV in her arm!

20. Some of us can't stand the idea of one more medical referral, one more hearing test, one more piece of expensive adaptive equipment or one more withdrawal scenario from a drug that has been working perfectly well in controlling a problem. Maybe we can stand it next month, but not today. When such recommendations are made, please be specific about how immediately they need to be implemented, the likely results of doing so and whether lack of implementation will cause harm.

21. Consider money when you make your recommendations. Some of our kids have cost six times what our houses did, and we're still not done.

Plaudits for Professionals

(We wrote this because many professionals we've dealt with have been terrific and we wanted people to know we appreciate those men and women.)

Kathy

1. My pediatrician did not abandon ship even when the first two neurologists we consulted found nothing wrong with my son. He saw the problem through over a period of years to effective treatment and eventual diagnosis. We needed his unswerving backing and we got it.

2. One doctor at the Mayo Clinic was particularly receptive. She made us feel that she had all morning to hear me out and discuss my son. Three doctors there confirmed the validity of my impressions.

3. Our pharmacist was always willing to discuss my questions about the drugs being taken by or considered for my son. He discussed drugs in far more depth than the doctors, suggested other anticonvulsants to consider and even made phone calls to drug companies for further information on side effects. His constant encouragement kept me from losing hope that a solution could be found.

4. After drug treatment finally began to work with my son, doctors became willing to abandon their reliance on clinical evidence as the only grounds for believing my son's problem might be organic. They became more interested in my observations and conceded that my son's case is unusual.

Jeannie

1. The people at the National Academy for Child Development put parental observations first and foremost. They treat our input as reliable and valuable. They believe -- how refreshing -- that we know our son because we live with him 24 hours a day.

2. Our physical therapist was helpful in showing us how and why a particular exercise was necessary. She was not afraid to share information with us.

Jan

1. Our pediatrician was up front and honest as soon as he recognized Sara's problems. He answered questions I had right away. If he didn't have answers, he looked for them and scheduled a conference with us for the next day. The timing was crucial because I wanted to know so much and informational delays were maddening.

2. The nurse who was present when Sara was diagnosed as having Down's syndrome asked in the aftermath if I wanted her to stay with me, if I wanted her to call my husband, if I wanted to talk with a mother of another Down's child. She gave me options in those first few agonizing hours.

3. A professional pointed me towards a support group, encouraged me and my husband to go and provided transportation to it the first time.

4. Although our pediatrician did not tell us to put Sara in an institution, neither did he put much credence in early intervention programs. However, he was always willing to note Sara's progress and listen to our reasons for believing in early stimulation and has since become enthusiastic about Sara's development. He now believes the stimulation program has made a difference and I applaud him for being open enough to change his mind.

5. In the beginning, I devoured information on Down's syndrome. The people at CDC (the Comprehensive Development Center) found me information on everything I asked about and found it quickly.

6. The nurse who was present at Sara's diagnosis realized that parents of special kids need to hear good things about their children just like any other parent. She spent a lot of time with me telling me how beautiful Sara is and pointing out such things as her long eyelashes.

Susan

1. Keough's surgeon sat down with us when we got to Salt Lake, explained her medical situation and then spent quite a while discussing his philosophy of medical care for children who will never be "perfect" or completely "cured." Now that I know how terribly busy and sought after he is, I am amazed at the time he took. We needed it desperately, especially since our first pediatrician had so casually offered us the alternative of letting Keough starve to death.

2. A couple of the nurses in Primary's newborn ICU took a particular interest in Keough. They told us how "tough" she was, that she was a fighter. They hauled out a Polaroid to take pictures of her with us. When we had to come back to Missoula without her, they sent us pictures every week. As they came to know us over the next two years, they'd joke that Keough is just as stubborn as her Dad and tell us how much she's taught them about Down's kids. Whenever Keough is back in the hospital, her friends literally stream in the pediatric ICU to see her and play with her. Two of the nurses have opened their homes to us whenever we're back in Salt Lake. They know that when Keough's in the hospital, it's a weird kind of vacation for me and they encourage me to get out of the hospital and take advantage of it.

3. Neither Keough's surgeon nor the pediatrician we switched to when she was 6 months old have ever pretended to know something they didn't. If I expressed concerns about her, they have believed there was reason to check it out. Their egos are strong enough and their knowledge vast enough that they have no problem with consulting specialists in other fields. They have treated me and my husband as rational, intelligent people. They have involved us in the medical process and have always made medical records available to us. They <u>like</u> our child.

4. Our home trainer let us know right away that Keough's handicap is secondary to her being, and that she likes Keough. She knows when it's time to dump the day's program and talk over coffee. She knows when one more medical referral or new program will be too much for us. She knows what she is doing and how to explain it to us. She has made us feel important.

Surviving The First Three Years: One Parent's Perspective

Susan Duffy

The discovery of a handicapping condition in one's child is, at best, upsetting and even the most stable of families can feel as if they have lost control of their lives on hearing the news. Although the discovery may be the initial point of stress, other stresses quickly arise: horrendous medical bills, relationships with family and friends, service agencies and their waiting lists, the public school system. Pediatricians who were just fine for previous children in the family turn out not to be so fine for the handicapped child. Friends who were thought to be rocks turn out to be made of crumbling sand. It can all cave in at once.

When I list the things that made the survival of my family possible after our daughter's birth, they fall in the the acronym HELPFUL -- humor, education, legwork, pediatrician, family/friends, understanding and luck. Each has played a major part in our effort to pull it all together.

Our daughter, Keough, born four years ago with a host of life-threatening birth defects and Down's syndrome, was flown to an out-of-state hospital when she was four hours old and didn't come home for three months. We made the 1,000-mile round trip to the hospital several times during those months, but when we were at home we felt as though our lives hung on the daily phone calls from the hospital in Salt Lake. A doctor on the phone usually meant bad news while the voice of a nurse meant things were okay. It was an emotional roller coaster I hope never to ride again. The night Keough was born and flew away from us, my husband and I cried until we had no tears left. Finally, one of us said, "We can't afford to lose our sense of humor over this." It was a start.

HUMOR. Because humor is so touchy in this kind of situation, it is all too often ignored, but humor can be the first step on the road to healing. No matter that it is ironic or black or ludicrous at best. If you can find something to laugh about, it helps put things into perspective. I remember three things that made me laugh -- admittedly with a touch of hysteria -- in the early days. The first was in the realization that, having lived in Japan for several years, I'd always said I'd like to have a child with oriental eyes and now I had one. The second came from walking into the regional hospital's

newborn intensive care unit and seeing all these sick little babies with Dixie cups taped to their heads. The cups were there to keep the babies from pulling out their IVs -- head veins are often the easiest to find on a baby -- but they made it look as though some kind of bizarre party was going on. The third was receiving our first month's bill from the hospital for $27,000 (please ignore this bill if remittance has been made) and a check from our insurance company for 32¢. So laugh. Cry when you need to, but don't be afraid to laugh, too.

EDUCATION. The more you know, the less scary the future looks. Parents need to have both concrete information about their child's condition and prospects and what I will call emotional information. The hospital social worker gave us two books to begin with, one explaining what Down's syndrome is and how early intervention helps and the other written by parents which let us know that the emotions we were experiencing -- even the ones we were ashamed of feeling -- were not abnormal and that we could and would move beyond them.

We were referred to a pediatrician whose youngest child has Down's syndrome. In his waiting room, we saw a large poster of a man with a little Down's girl riding on his shoulders -- both of them laughing their heads off -- with the legend "Children value themselves as they are valued." The man in the poster turned out to be the pediatrician we'd come to see.

Four things stand out in my memory of our conversation with this man -- first, that children with Down's syndrome look like their parents. This seems obvious to me now, but at the time it was a revelation. When I held Keough in the hospital later that day I examined her in a new light and saw my husband in her. She stopped looking like Winston Churchill and became part of the family.

Second, we were told to be aggressive about Keough's hearing when we got her home. We hadn't known how common hearing problems are for Down's children due to their narrow ear passages -- and his advice has kept us alert to potential problems. If you can't hear, it's difficult to learn and we want Keough to be as open to the world as she can be.

The pediatrician mentioned in passing that his wife is a judge -- a brief remark that reopened my personal world. It said to me that parents' lives can continue to grow, that Keough was an addition to -- rather than a termination of -- our dreams and plans, that my career goals might be slowed but would not have to be completely sacrificed to Keough's needs. I really needed to hear that.

Lastly, I remember inwardly scoffing at his statement that we would quickly become the experts on Keough's problems and capabilities. He told us that while he had always thought of himself as attuned to the problems of families with handicapped children, the birth of his daughter four years before had opened his eyes to problems he had never before considered in his medical practice. I have since found that he was absolutely right. It is the rare professional who really understands what our family goes through, and few doctors know much beyond the basics of Down's syndrome or, so other parents have told me, other childhood handicapping conditions.

LEGWORK. When we left Keough in Salt Lake to come home, we were armed with information and a hopeful outlook as opposed to the myths and fears with which we had arrived. Because we had met the state superintendent of schools during her reelection campaign, we took a trip to see her and find out what services would be available for Keough when she came home. This was the beginning of our legwork stage and I'm not sure the legwork ever ends.

The superintendent put us in touch with three outfits. The first was the Comprehensive Development Center (CDC) which offers evaluation and home-training services. We guessed at Keough's homecoming date and made an appointment for an evaluation. We then contacted the HCEEP program based at the state university in our town. I am convinced that the earliness with which we began developing a relationship with the people running this program is responsible for Keough being the youngest child -- 22 months -- that has so far been admitted to their preschool. The third contact offered was with the public school system, a contact on which I didn't follow through at the time because I thought it could wait. I now see the error of that decision because shortly therafter the school system dropped its preschool special education program and I spent the second year of Keough's life joining with other parents in the battle to have it reinstated. (Montana is a "permissive" state, a term I find ludicrously close to double-speak.) We were, by the way, successful -- but it took a lot of energy and effort I'd rather have spent on some other things.

Once Keough was set up with services and our home trainer began coming to the house once a week, we began to feel more in control. At last we were able to begin what we thought of as the "real" work, which Keough's prolonged hospitalization had delayed. Our lives began to fall into a routine most welcome after the chaos of Keough's birth and medical problems. Legwork pays off in concrete, tangible results. It shortens your time on waiting lists, gets your child services and lets people know you're out there. Visibility is one of the best tools parents have at their disposal.

PEDIATRICIAN. A compassionate, knowledgeable pediatrician is a necessity, the key element being compassion since an uninformed but willing doctor can always become better informed.

Our first pediatrician was neither knowledgeable nor compassionate. Twenty minutes after Keough was born, he offered to let her starve in the local hospital's nursery, and when she returned from Salt Lake -- three months and $120,000 later -- and developed further life-threatening problems due to an undetected birth defect he did not lift a finger, much less a telephone, to attempt to discover what was wrong. His attitude, we were later told by one of his former employees, was that we should let Keough die, that Down's children are "gorks" and "only useful as pets." This was a young doctor, by the way, not an old curmudgeon. When I think of it now, my rage is still indescribable.

Most parents' negative experiences with doctors will not be this extreme, but many will find that their efforts to maximize their child's potential are not encouraged by their doctor. While most physicians have given up suggesting early institutionalization, few are touting the benefits of early intervention. At best, an unsupportive pediatrician is an energy drain and parents should be aided in finding one who will support their efforts if they cannot educate the one they began with.

We now have an excellent pediatrician -- in fact, all the pediatricians with whom he is practicing are extremely supportive -- but we are appalled by how little we knew about our legal rights and personal responsibilities in the health-care system when we began.

FAMILY/FRIENDS. We have been fortunate in that almost everyone in the family rallied around from the beginning. Those who were too upset to deal with the idea of Keough at first (the grandfathers) came around quickly when they actually met her. Keough's cousins have been taught by their parents to be proud of her, to applaud her successes and to help her when she needs it. They look forward to her visits. Friends and acquaintenances have amazed us with their interest and several we thought we knew well before Keough's birth have confided since then that a brother, sister-in-law or cousin has Down's syndrome. The positive ripple effects of Keough's birth have been enormous.

Keough's godmother, Marnie, has been a godsend for us and if I were to give new parents any advice it would be to choose their child's godparents wisely. If there is no tradition within the family of having godparents, start one. Because Keough has breathed by means of a tracheostomy tube for the last 3½ years, either my husband or I must be alert for trach-clogging noises day and night. Marnie has established a pattern of taking Keough to her home Friday afternoon and returning her to us at noon Saturday. This has given us one good night's sleep each week and time for my husband and I to do things that would otherwise be impossible. It gives Keough the opportunity to be around other people and do things with Marnie that she doesn't do with us. We joke about having to write out legal visitation rights should we ever have to move out of town. Marnie has become Keough's second mother. That Marnie is also a lawyer certainly doesn't hurt when we think of Keough's future.

We have appointed guardians for Keough, should we die, who we know would care for her in a manner that would emphasize her best interests, and who we know would never place her in an institution. We are beginning to learn about the maze of and pitfalls in estate planning, figuring out how to ensure that Keough will be able to have what she may need without placing her in the position of owning tangible assets that would make her ineligible for government services. (The current limit is $1,500 of goods.)

Of course, it hasn't been all roses. Before Keough's birth, we had asked another friend to be a godmother, but after the birth she withdrew from us. For awhile I felt very bitter about this, but our relationship eventually smoothed out. Still, our friendship will never be as strong as it was. Many parents of children with handicaps find their other relationships shifting after the handicap is discovered, making a difficult time even worse. At the risk of sounding cold, I will say there are too many people who do care for me to waste time and energy -- already in short supply -- on those who don't.

UNDERSTANDING. By understanding, I mean empathy -- the ability to place one's self in the other persons shoes. It is the single most important quality professionals can offer families. The first professional to offer us understanding was Keough's surgeon at Primary Children's Medical Center in Salt Lake. This skilled and busy man took the time to explain not only Keough's medical problems, but also his philosophy of medical treatment for children whose ills can never be completely "cured." If physical problems can be repaired, he said, they should be. Mental retardation or the presence of chromosomal abnormalities should have no bearing on the decision to save a life. If the child cannot live long no matter what medical action is taken -- such as a child born with an exposed brain -- then perhaps a different decision should be made. I thought of this when Baby Doe's case was publicized. How different it might have been had they known a person like Keough's surgeon.

Professionals can be wonderfully human or they can be policy-ridden bureaucrats. Those who work with families need to know when it's time to throw over the plans for the day and have coffee with the mom instead. They need to be able to understand both the positive and negative sides of having the child in the family. They need to fully comprehend that it is not only the child who is at risk, it is the entire family.

Professional training tends to stress the idea that a "good" professional does not become emotionally involved with a family. (A really "good" professional would say clients instead of family.) Baloney. A textbook-style professional may not burn out over the years, but the lack of emotional involvement will raise barriers that make that person much less helpful to families desperately needing help. To me, a good professional is one who can laugh and cry, who knows and can teach me what needs to be done and who genuinely likes my child -- someone who can understand what it's like to be in my shoes. Our home trainer took Keough for the weekend twice in the early days so we could get away and I knew she'd made the empathetic connection when she and her husband adopted a baby and found themselves looking for Keough's suction machine the first few nights they got up with their own child.

LUCK. Ours has been good. Our family and friends love Keough and support our efforts to help her progress. We have an excellent pediatrician who believes in Keough and in early intervention. We have a surgeon who believes in the value of handicapped children. Our experience with service providers has been good; when I hear from families whose home trainers are less than sensitive to the family as a whole, I thank my stars that we drew a person who is both superb in her field and someone I can call a true friend. For myself, I also thank my husband. From the moment Keough's problems were discovered, he has been unwavering in his belief that our daughter is worth all the physical, emotional and financial stress she has brought us.

On a more somber note, we are both incredibly lucky in that we have a child capable of giving back in love 10 times anything we can give her. There are too many parents who do not have this, and I do not know how these parents survive. If there is anyone in the world who should be applauded, it is parents of children who can return little, if any, of the love they are given. All of us -- family, friends and professionals -- have to pull together if these families are to be able to survive.

EPILOGUE

When our daughter was born, my husband and I were faced with making a rapid decision as to whether we would remain in Missoula, Montana, or return to Washington, D. C., where my husband had a good job. Of primary importance was our medical insurance, which was tied to my husband's job. Once we found he could fill a position for his employer in Montana, our options became less limited.

If we chose to return to Washington, we knew medical facilities would be closer and many early intervention services would be available. Our income would be good. We also knew that it would mean a 60-hour work week for my husband, living among strangers and more impersonal relationships with medical people. Just finding a parking place near a medical facility can become an enormous hassle in D.C.

If we chose to stay in Montana we would have family and friends nearby, a less stressful working situation for my husband and the opportunity to lead a more normal life. While early intervention services were fewer, they were available. However, staying entailed a large cut in income and traveling 500 miles to Salt Lake for Keough's surgeries. We decided to stay.

The advantages of living in a rural area are many. While there are fewer services, there are less people competing for those services. Though distances are vast, people tend to know each other across the state, and people in authority are generally more accessible than those in urban areas. Here in Montana, almost anyone who wants to talk with the governor can do so. If you become involved with the public school system, the superintendent will remember your name. The state superintendent will put you on the department's mailing list. Your letters will be published in the local newpaper and, if you become an advocate, local radio and television talk shows are happy to have you speak on their programs. All in all, it is easier to become involved in the public process and, once involved, much easier to accomplish your goals. You don't have to be superhuman, you just have to be determined.

Parents, Professionals and Conflict

Susan Duffy

There will always be conflicts between parents of handicapped children and professionals offering services to those children and their families. Perhaps the biggest reason for these conflicts, and the most insoluble problem, is that there is a vast difference between understanding a situation intellectually and understanding that same situation emotionally. This is a problem for both professionals and parents.

While professionals may really know their business, unless they have actually lived with and been responsible for a handicapped child, it is probably impossible for them to fully comprehend the 24-hour-a-day, 52-week-a-year implications of that child's problems for the rest of the family. Even if the professional has worked in a group home or institutional settings, the experience is not equivalent because the professional was paid for the work, had built-in vacations and spent more time away from the job than on it.

On the other hand, it is difficult for many parents to understand the stress many professionals are under -- particularly in these times of tight money and large caseloads -- from working with so many families whose problems are extremely varied and whose needs are often so much greater than the resources available from several agencies, much less one individual provider.

The most comprehensive discussion I have seen of these issues is Dr. Helen Featherstone's book, A Difference in the Family. Featherstone was a professional in the field before she became the parent of a severely handicapped child and I would urge all professionals who work with handicapped children and their families to read the book.

There are also conflicts which arise, including conflicting policies, turf wars, hidden agendas, opposing theories of child development and inter-agency personality conflicts. There are more politics being played among service agencies than we may care to admit and the wise parent will learn how to play the game, if only to avoid being caught in the crossfire. The lucky parent will find a professional willing to help decode the rules of the game.

Many of the problems professionals have with each other are caused by differences in their academic training. Others are caused by policy differences in the agencies they work for. Some problems that arise are purely personal and grow out of the fact that, at least in rural areas, everyone tends to know everyone else and newcomers are often viewed with suspicion. The cumulative differences lead to different expectations on the professional's part as to who is the target of service delivery and what parents' roles are in the process.

Professionals tend to self-select into two groups regarding parents: those who see parents as passive participants in the process and resent parental interference with the planned program, and those who view parents as active, informed consumers and encourage their participation in eliciting progress from their child. Parents, of course, cover the spectrum between passivity and activity, but most will grow in strength and knowledge if given any impetus to do so.

Many problems parents have with professionals seem to be the result of the compartmentalized approach to education fostered by our academic system. For instance, those who study early childhood development may or may not also have studied adult psychology and learning theory. Unless the early-interventionist is comfortable with both child and adult learning, there can be problems. Those who offer medical services for children rarely know much about -- or feel they need to know about -- a child's intellectual development.

Compartmentalized knowledge leads to narrow approaches and professionals may or may not be willing to admit a lack of personal expertise in an area, may or may not have faith in the ability of another professional to fill in the blanks. In situations where a parent has been given conflicting advice and is forced to choose between approaches, the professionals whose advice is not taken may view the parent as having rebuffed their professionalism. It may even be viewed as an outright personal betrayal. The parent is caught in the middle.

Compartmentalization leading to a narrowed outlook can also arise from interagency agreements on who is responsible for which parts of the early-intervention turf, agreements that usually have been arrived at for the sane reason of avoiding unnecessary duplication of services but which can be extremely unhelpful if followed blindly.

For example, Agency A may recommend that a family or child have a genetic evaluation done by Agency B, which is in another town. Agency A has made a good faith recommendation, but for the family there is a great deal more involved.

Agency A may fail to coordinate the appointment (seeing that as the family's responsibility), fail to arrange for defraying the cost (Agency C has the money for such evaluations), fail to understand the implications of travel for the family (Agency D is responsible for travel expenses while Agency E is the only group that can provide respite care for the family's other children), and fail to share the resulting information with other agencies (since Agency B did the evaluation, it's B's responsibility).

What seemed like a simple, reasonable recommendation from A's point of view can become an enormous undertaking for the family if A does not follow through. Obviously, agencies need to have general policies, but those policies must be flexible. Every family is unique in its problems and outlook and some will require more of a professional's time than others.

If there is one "rule" I believe should be done away with forever, it is the idea that a real professional does not become involved with or emotionally attached to families he or she works with. We are all humans, not sets of flow charts, and this humanity needs to be recognized by all concerned. Policies are developed to foster processes, not to fit all and sundry into a preconceived mold. A professional who cannot see this should not be in the field of human services.

There are other more personal problems families of handicapped children tend to encounter in their relationships with professionals. Those I will address are problems with pediatricians, evaluations, guilt, authority and control. The chronological order in which parents face these problems varies from family to family, but most families will have to deal with at least some of these problems at one time or another.

PEDIATRICIANS. One of the first professionals parents meet is the family pediatrician. Many parents have found themselves in the position of questioning their doctor about what they perceive as a developmental problem only to be deflected with the comment that the child will no doubt "grow out of it." Doctors seem to be extremely reluctant to make a diagnosis of delayed development until the problem reaches the point where it can no longer be denied. While this is understandable (no one wants to be the bearer of bad news unless it is unavoidable) and while it may temporarily mollify the parents (no parent wants to hear bad news), this wait-and-see attitude can cause real harm as a family waits in fear and hope for their child to "grow out" of a condition that early-intervention services could be ameliorating. Delayed diagnosis can also cause greater emotional damage in the long run to a family that has been proceeding in the belief that everything is fine.

For parents of the child born with an obvious handicap, it is the manner in which the aftermath of the announcement is handled that really counts. Let's face it, there are doctors who just don't see much value in the lives of children born with particular handicaps. They don't like them, they don't want them in their waiting rooms and they wouldn't do their best to save the child's life in an emergency. I believe parents' lives would be much easier if these doctors would just come right out, say what they think, and direct parents to a doctor who is sympathetic and does see value in the child's life. Families of handicapped children need pediatricians who are allies, not sources of further frustration.

Early-interventionists have a great deal of work to do in the area of educating medical personnel about handicapped children, their families and the positive effects of early intervention. Furthermore, early-interventionists can and must serve as intermediaries between doctors and families having problems with them. It is difficult for parents to decide to change doctors because most of us grew up believing that physicians were some kind of demi-gods. Old habits die hard, but as my husband says, it is worth remembering that someone has to graduate in the bottom 10 percent of each medical class.

EVALUATIONS. When a child has been referred for a developmental assessment -- even if the parents are the persons referring -- the evaluation is going to be difficult for the family. It will provide the first hard evidence of delays and no matter how well parents may know intellectually that their child has problems, their emotions are involved and not easily reined in.

Even when a child has been involved with early-intervention services for some time, the periodic evaluations of the child's progress are hard on parents. No matter that the parents have seen even great progress in their child, developmental tests are normed on regular kids and the handicapped child is always going to be behind in comparison. Parents may be able to ignore these comparisons in their daily routine, but the day that test results are discussed is almost always a tough one and professionals need to be aware of this. When one is working with many families and children, it can be easy to be insensitive to individual pain.

A double-bind in which parents can be caught when it comes to evaluations is the conflict of wanting their child to do well while knowing that evidence of real progress may cut the family off from the very services they need. SSI payments, for instance, depend on a child doing relatively poorly. No matter what the results of testing are in such a situation, there may be little cause for rejoicing. If the child is doing well in comparison to non-handicapped children, the family will be ineligible for SSI payments they may really need. If the child is not doing well in comparison, that difference is once more thrown into harsh relief and all the money in the world will not make the parents feel better. There is little a professional can actually do about this other than to be there for the family, understand and accept their emotions, and be a friend. That's quite a lot, when you think about it.

A third problem some parents will encounter with evaluations is that the available tests simply cannot always tell what the child's abilities really are, but may show the child to be an an extremely low level of functioning. Professionals must be aware of the need to explain the difference between norm-standardized tests and criterion-referenced tests to parents in this situation. Tests are not normed, for example, on quadraplegic spastics and such a child's intelligence must be inferred from other things.

As per our belief in the godliness of physicians, most of us have been programmed to accept test scores at face value. Parents of children with unique problems need to be assured at the outset that while certain tests are required for admittance to a program or are necessary for the family to become eligible for other services, the scores should not be allowed to crush the family's hopes or lessen the family's interaction with the child.

GUILT. Many, if not most, parents feel various degrees of personal guilt when their child is born with a handicap. The guilt tends to be unfounded since there is usually nothing the parents could have done or not done that would have changed the situation. Nevertheless, the guilt exists and parents must work through it in their own time. Compassionate professionals armed with good information can, of course, speed up the process, but need to be sensitive to how quickly they can move ahead on programmatic ideas. Child-find searches are being so successful these days that parents are often referred and contacted quite early in their emotional journey.

Although the arrival of home-based services is generally greeted by parents as a life raft would be greeted by a drowning man, professionals should be aware that the very existence of these services can form the basis for a new kind of parental guilt. While parents are being told that they will become their child's best teachers and that the programming techniques they will learn will help their child progress, the unvoiced flip side of all this positive thinking is that a parent's failure to teach correctly or work often enough with the child will lead to a lack of progress, if not regression.

From a parent's point of view, that's scary. Not only has the parent produced an imperfect child whose imperfections -- as in the case of a child with Down's syndrome or cerebral palsy -- can never be completely fixed and not only is the proposed course of action a seemingly endless project without guarantee of success, but the parents are now responsible for progress or the lack of it.

While it may seem unreasonable for a parent to fear this kind of responsibility since parents are normally considered to have the responsibility for raising their children, it is the intensity of the responsibility that is frightening and needs to be understood. If Dad doesn't go out and throw the ball around with his non-handicapped son Billy for a week, Billy isn't going to lose the ability to do it. A handicapped child may not only lose the ability to throw the ball, he may lose the ability to pick it up.

Assertive parents will give themselves periodic "vacations" from the intensity of the situation. Non-assertive parents often need a professional's validation in order to take time off without feeling incredibly guilty.

AUTHORITY. Maybe this should be called something else. May it should be called "Broadcasting and Receiving." It all ties into the idea that the difference between a professional and a parent is that the professional knows things a parent doesn't and is trying to communicate those things to the parents -- or should be.

Professionals trained to work with children may be uncomfortable working with adults and may attempt to cover this discomfort by being more "professional." This often manifests itself, for example, in the use of professional jargon. Such jargon is a familiar kind of shorthand language for professionals, but all jargon presupposes agreement on certain assumptions. Parents may or may not agree with the assumptions held by the professional, but if they don't know what the assumptions are, no one will know if they do or not.

Jargon makes it difficult for parents to learn what they need to know in order to help their child. It keeps them separated from and slows down the process. Lastly, and devastating to any personal relationship between the parent and the professional, the use of jargon is a way of saying, "I'm the person who knows and you're the person who doesn't. I'm in control here, not you."

While a professional may be saying and feeling all the right things, the manner in which it is said may be perceived by parents as a signal that the professional, although saying the parents will be terrific, doesn't really believe the parents are all that trustworthy or smart. These subtle signals may be unintentional and the professional might be appalled with himself if they were pointed out. Professionals need to be aware of how they come across to parents.

Sometimes professionals are so knowledgeable and excited about what they are doing that their knowledge spills out in cascades, overwhelming parents with the enormity of the undertaking. Intellectual overloads can be avoided by taking one thing at a time, gauging how much information the parents can absorb in one session and being aware of sensitive areas.

For me, medical referrals are sensitive because my daughter has already been through so much medically. The thought of shelling out more dollars for additional referrals, when our debts are so great for previous medical care, is terribly depressing.

When professionals suggest a course of action that will cost parents additional money, both the need for such action (A. It's imperative. B. It would be good if ... C. It might help to ...) and the time frame in which the action should be taken (A. Immediately. B. In two or three months. C. By the time the child is 3) should be made very clear. A casual remark made by a professional can be perceived as a bombshell by parents, and professionals must be ready to follow through on those remarks.

CONTROL. Families of handicapped children feel their lives are out of control for varying periods of time. It is important to understand that this feeling of lack of control can be a recurring experience. I find I am leery of surprises these days as they tend to upset the equilibrium I have worked hard to establish. A professional's job should include guiding parents into actions that will help them regain control of their lives. It has been said many times and will bear repetition again that it is not only a handicapped child that is at risk, it is the child's entire family.

One of the first things Jan, our home trainer, told us was that her goal was not only to show us how to teach our daughter specific skills, but to teach us how to teach her so that if we ever found ourselves without services we would still know how to facilitate progress. After 3½ years of working with Jan and my daughter, I know I would hate to see Jan go -- she has become a good friend as well as someone whose professional abilities I respect tremendously -- but she has come close enough to her goal that if we were suddenly shoved out of the nest to fly on our own, I think we could. In these times of uncertain and shrinking funding for human services, it's a real comfort to know we've learned well.

The first thing Jan did when she initially came to our home was get down on the floor and play with our daughter. It made me feel good. Most of our friends, though very supportive of our daughter, treated her somewhat gingerly when it came to physical contact since she still had a feeding tube inserted in her stomach, but Jan launched right in.

She has told me since that this was a calculated move and something she tries to do each time she begins working with a new family. It tells them she likes their child, it puts her physically at a lower level than the parents and it demonstrates that she's an informal, non-authoritarian person. It's very effective. More professionals ought to try it.

In summary, I think real professionals don't have to worry about proving their professionalism. They know their own worth and do not have to demonstrate their position of authority. More than anything else, perhaps, professionals need to use their instincts and trust their own emotions. For professionals who work with children and families in early intervention, it is of utmost importance that they be themselves and not merely someone filling a job description.

LIST OF MATERIALS

CO-TEACH Preschool Programs

Division of Educational Research and Service

School of Education

University of Montana

Missoula, Montana 59812

(406) 243-5344

11/91

OVERVIEW OF THE CO-TEACH PRESCHOOL PROGRAMS

In 1981 the University of Montana received a three-year HCEEP grant to develop a comprehensive center-based program that would be responsive to issues in rural early intervention. The resulting Big Sky Preschool Model incorporated "best practices" from other model early-intervention programs. Monographs of the HCEEP Rural Network, data-based journal articles, efficacy studies, and discussions with colleagues led to the identification of issues in rural early intervention and potential solutions. In addition to replicating others' successful practices, the Big Sky Model utilized several innovative strategies, including an interdisciplinary approach, reverse mainstreaming, non-categorical enrollment, integrated parent and staff meetings, and daily progress evaluation.

In 1985 the University of Montana received another HCEEP grant to develop a transition model for rural preschoolers. The project, entitled "Carry-Over Training to Enhance the Achievements of Children with Handicaps" (CO-TEACH), was characterized by a transdisciplinary approach, with components that address local norm referencing, transitioning into and out of preschool, developing parents' expertise, and follow-along of preschool graduates.

In 1987 HCEEP awarded the University of Montana another grant to utilize videotapes in the transition from preschool to kindergarten and the home environment. The project, entitled "Video-based Information to Document Educational Objectives for the Support of Handicapped Children Across Receiving Environments" (VIDEO-SHARE), incorporates the use of video-based assessment of classroom survival skills, videotape records of therapeutic interventions for receiving classroom teachers during transition, and videotape exchange with parents to guide carry-over of skills into home and preschool environments. These transition components are integrated with the Big Sky Preschool and the CO-TEACH components. In that regard, the VIDEO-SHARE Program endeavors to build upon effective practices for early intervention in rural settings.

In 1990 HCEEP awarded the University of Montana a three-year Outreach grant to assist Montana schools to implement special education preschool programs. Materials and technical assistance are available through the Outreach Program.

In 1991 HCEEP awarded the University of Montana a three-year VIDEOSHARE Outreach grant to assist Montana schools and service agencies to incorporate video-based assessment into their existing practices.

The VIDEO-SHARE Outreach and CO-TEACH Outreach Programs offer a variety of materials of interest to early intervention service providers, professionals in training, and parents of special-needs children. Recipients of these materials are encouraged to make copies of non-copyrighted materials for use in educational programs, to adapt forms and procedures to their own circumstances, and to provide feedback to CO-TEACH staff. Requests for materials and feedback should be directed to the cover address.

ACKNOWLEDGMENTS

Effective early intervention requires a team effort. Members of the VIDEO-SHARE Outreach "team" are pleased to recognize individuals and agencies who have provided ongoing sponsorship on behalf of young children with disabilities and their families. Support by the Handicapped Children's Early Education Program, Office of Special Education Programs, United States Department of Education, is gratefully acknowledged. The VIDEO-SHARE staff also thanks Raymond Murray, Vice-President for Research at the University of Montana, John Pulliam, Dean, School of Education at the University of Montana, Glendon Casto, Director, Utah Developmental Center for People with Handicaps, and the parents and children who have taught us so much. Particular appreciation is extended to Ruth Ward, HCEEP Program Officer, who always manages to find the time for listening and sharing.

Dissemination of Rural Network Monographs has been made possible by authors, editors, and board members of the HCEEP Rural Network who unselfishly contribute their expertise to our shared mission to provide optimal services for young handicapped children and their families.

Preparation of this document was supported by Grant #GOO8000191 (Big Sky Model Demonstration), Grant #GOO8303567 (Big Sky Outreach), Grant #GOO8530084 (CO-TEACH Transition Model Demonstration), Grant #GOO8730535 (VIDEO-SHARE Transition Model) and Grant #H024D00029 (Montana Early Intervention Outreach) from the Office of Special Education Programs, U.S. Department of Education. The opinions expressed herein do not necessarily reflect the position or policy of the U.S. Department of Education, and no official endorsement should be inferred.

THE CO-TEACH MODEL REPLICATION PROGRAM

Concurrent with the implementation of **Public Law 99-457**, the CO-TEACH Preschool Program has recently developed a series of modules - **The CO-TEACH Model Replication Program** - which assist administrators and classroom teachers in designing, organizing, and implementing special preschool services. Modules which are currently available include:

Module #1: **Organizing the Special Preschool**
- This module describes in detail what needs to be done to ready the classroom environment for students before school starts. Sections of the module cover information on purchasing and gathering materials, communication among team members, arranging the physical layout of the classroom, and a helpful appendix which includes myriad reproducible forms, recipes, preschool newsletter samples, staffing and parent helper schedules, learning center guidelines and a sample preschool floor plan.

Module #2: **Implementing the Special Preschool Program**
- This module addresses key issues involved in initiating services for young children with disabilities and their families. At a fundamental level, these include decisions regarding "what to teach" (curriculum and Individualized Education Plan contents), "how to teach" (methods of instruction and service model), and "when to teach" (lesson planning and program scheduling). The module includes discussions of evaluation and curriculum, strategies for the implementation and modification of curricula, individual education plans (IEP), instructional strategies, teacher and staff responsibilities, and classroom scheduling.

Module #3: **Forging Partnerships with Families**
- This module focuses on basic methods to invite, develop and enhance the partnership of parents and families in the preschool program. Sections include information on understanding the impact of the child with disabilities on the family, establishing trusting relationships with families, recognizing and utilizing parental expertise, understanding the impact of intervention on the family system, and individualizing family involvement. Retrospective anecdotes from the Western Montana Support Group for Parents of Children with Special Needs add a valuable "consumer" perspective to this module. Appendices include forms to encourage home/school communication, a suggested reading list for families and professionals, and a "wish list" compiled by the support group entitled <u>What Parents Want from Early Intervention Professionals.</u>

Module #4: **Teaching through Play**

- Play is a developmentally appropriate learning experience for all preschool aged children. Thus, in the special education preschool classroom, the role of the teacher becomes one of facilitating learning through play. This module highlights (1) the value of play as a learning tool, (2) setting up a developmentally appropriate environment that encourages spontaneous involvement and learning, (3) recognizing "teachable" moments and providing naturalistic (incidental) instruction, and (4) providing direct instruction within the play environment. Appendices include a suggested list of books and tapes for the preschool classroom.

Module #5: **Classroom Behavior Management**

- This module focuses on techniques and suggestions for effectively creating a balance between managing the behavior problems of small children and striving to create a positive, appropriate setting in which optimal learning may occur. The module addresses some ways in which many behavior problems may be reduced or prevented through careful planning and positive classroom management. Included are discussions of placement options, selection of curriculum, selection of materials, arrangement of the educational environment and suggestions for planning the instructional format. In addition, therapeutic treatments are included which clearly define steps that can be taken when behavior problems occur. Also suggested are methods of observing and documenting behavior change and determining the effectiveness of interventions.

Module #6: **Preparing for Transition**

- An important role of the early childhood special educator is planning a classroom environment and activities to encourage the optimal development of the child. This development must focus on the current needs of the child, as well as look ahead to future school placements. For children with handicaps, the least restrictive and most likely placement to come after preschool is in a public kindergarten program. **This module focuses on strategies for preparing children for kindergarten success.** Included are suggestions for advance planning with the teacher who will be receiving the child in the next school year, strategies for implementing and practicing "mini" transitions within the preschool day, planning for effective interagency Child Study Team meetings, and techniques for "follow along" once a child transitions out of preschool to a new classroom environment.

COST:

- $6.00 per individual module
- $30.00 for series of all six modules

MERIT CURRICULUM

Montana Early Intervention for Readiness in Transition:

- MERIT Curriculum focuses on classroom and social skills which are functional and which will generalize across environments. These kindergarten entry skills enable a child to benefit and achieve in a mainstreamed and least restrictive environment.

- The basic components of the curriculum include Individual Transition Plan Assessment, Quarterly Progress Report, Individualized Monthly Planning Sheet, and Teaching Record of Instructional Programs. Embedded into the curriculum is an assessment system which continually monitors the child's progress. The domains of the curriculum and assessment include academic readiness, social/emotional skills, and activities of daily living. The skills assessed and taught have been developed from a list of Kindergarten Entry Skills compiled by Montana kindergarten teachers.

- CO-TEACH Individual Transition Plan Assessment: Component I contains a pre- and post-preschool assessment, pre-kindergarten assessment to monitor skill maintenance, and Index of Teaching Records cross referencing the Individual Transition Plan Assessment with the MERIT Curriculum and the Brigance Assessment Developmental Milestones.

- MERIT Curriculum: Component II contains a Quarterly Progress Report that records progress of IEP goals during the academic year, an Individualized Planning Sheet that plans for which Instructional Programs will be taught weekly or monthly, and the Teaching Records of Instructional Programs that contain task-analyzed IEP goals, data collection system, and direct instruction techniques.

- $55.00

MATERIALS BY AND FOR PARENTS

Common Ground:

- A series of essays for professionals and families who unite to help young children with special needs. Packet includes:
  - Acceptance is Only the First Battle
  - Building Effective Parent/Professional Partnerships
  - What Parents Want from Early Intervention Professionals
  - What Parents Valued Most from Early Intervention Professionals
  - A Mom's Perspective on Early Intervention
  - The Birthday Invitation
  - What Professionals Can Do to Help Marriages Survive
  - The Risk of Divorce: What Parents Can Do to Help Themselves
  - When I Felt Really Bad, I Read a Book...
  - Welcome to Holland
  - Skyriding
  - Suggested Readings for Professionals and Families Seeking to Form Effective Partnerships
- $12.00

Robbie:

- A narrative story by parents, for parents describing rationale and procedures of the Big Sky Preschool Model, and common experiences of families who participated in the Big Sky Program.
- 37 pages
- $5.50

Acceptance is Only the First Battle:

- A description of problems experienced by parents in obtaining optimal services for their special-needs children.
- 43 pages
- $2.50

Suggested Readings for Professionals and Families Seeking to Form Effective Partnerships:

- A listing of publications, books and newsletters addressing parent, professional, and family issues. Title, author(s), publisher and year are noted.
- 2 pages
- $1.00

CLASSROOM PRACTICES

CO-TEACH Procedures Manual (Vol. I): The Service Model:
- Incorporates the Big Sky Rural Preschool Model
- Approximately 150 pages
- Includes copy-ready forms
- $25.00

CO-TEACH Replication Site User's Guide:
- An overview of the CO-TEACH Model
- 24 pages, no forms
- $3.50

A Guide to Preschool Activities for Children with Handicaps:
- A listing of classroom activities, denoting time, the activity, child objectives, instructional therapist objectives and data collection.
- 4 pages
- $1.00

TRANSITION PRACTICES

CO-TEACH Procedures Manual (Vol. II): The Transition Model:
- A guide to replication of the transition components of the CO-TEACH Model, including Transitioning into Preschool, Parent Expertise, Follow Along, and Buddy Systems.
- Approximately 100 pages
- Includes copy-ready forms
- $20.00

CO-TEACH Self-Instructional Guide to Local Norm-Referencing; Predicting Transition Success:
- Provides instructions, materials, and protocols for accomplishing an objective prediction of how well an individual child will "fit" in instructional and social activities of a potential less-restrictive receiving environment.
- $10.00

CO-TEACH Individual Transition Plan Assessment:
- Also available separately.
- $20.00

RURAL NETWORK MONOGRAPH SERIES

What's Rural? An Overview of Successful Strategies Used by Programs for Young Handicapped Children:
- Edited by Patricia Hutinger
- 26 pages
- $4.00

Cost Effective Delivery Strategies in Rural Areas: Programs for Young Handicapped Children:
- Edited by Talbot Black and Patricia Hutinger
- 41 pages
- $6.00

Securing Funding in Rural Programs for Young Handicapped Children:
- Edited by Corinne Garland
- 33 pages
- $5.00

Effective Strategies in Collection and Analysis of Cost Data in Rural Programs:
- Edited by Talbot Black and Patricia Hutinger
- 48 pages
- $7.00

Influencing Decision Makers:
- Edited by Louise Phillips
- 29 pages
- $4.00

Training, Recruiting, Retaining Personnel in Rural Areas:
- Edited by Patricia Hutinger and Bonnie Smith-Dickson
- 45 pages
- $7.00

The Transportation Situation in Rural Service Delivery:
- Edited by Patricia Hutinger
- 20 pages
- $3.00

Interagency Coordination: A Necessity in Rural Programs:
- Edited by Steve Threet
- 48 pages
- $7.00

Effective Collaboration Among Health Care Professionals: A Necessary Condition for Successful Early Intervention in Rural Areas:
- Edited by Bonnie Smith Dickson and Patricia Hutinger
- 49 pages
- $7.50

RESEARCH ARTICLES

Single copies of the following research articles are available for educational use at no cost.

Social Interaction in an Integrated Preschool: Implications and Applications:

- This study, co-authored by Richard A. van den Pol, David P. Rider and colleagues, investigates therapeutic interventions to encourage meaningful, sustained interaction among integrated play groups in mainstreamed preschool classrooms. Local norm-referencing methods were used to evaluate individual child success. This study systematically replicates basic research findings that "choice behavior" is influenced by complex ecological factors. It also replicates other applied research studies which have concluded that preschool playmate choice can best be influenced by careful adult encouragement and supervision. Moreover, this article demonstrates how child-focused feedback to adult teacher aides can positively affect adult performance, which in turn positively influences children's social interactions.

Teaching the Handicapped to Eat in Public Places: Acquisition, Generalization and Maintenance of Restaurant Skills:

- This study by Richard A. van den Pol and colleagues, demonstrates that simulation methods, similar to those used to train airline pilots, can be used to teach "community survival skills" to special high-school students. The consequences of restaurant customer errors admittedly are less severe than the consequences of airline pilot errors. However, a combination of role-playing techniques and photograph-recognition training was so effective that no in-restaurant training was required. Thus, travel time and costs were reduced and students' dignity was preserved due to few errors in restaurants. All students were able to use novel restaurants, and all students maintained their skills at a one-year follow-up check. Since this article was published in 1981, replications by other researchers have indicated that a combination of simulation and in-restaurant training may be most effective for students who learn particularly slowly.

Models of Assessment and Treatment in Child Behavior Therapy:

- This 29-page book chapter, co-authored by Philip Bornstein and Richard A. van den Pol, describes considerations in the selection of child behavior assessment and treatment strategies. Current issues are reviewed and exemplified in a case study of an encopretic child.

VIDEOTAPES

All videotapes are produced in standard VHS format. We believe the contents of the VIDEOSHARE tapes are valuable, although the technical quality may be reduced due to multiple duplication and consumer grade production equipment.

Children with Disabilities: Family and Marital Impact. Division of Educational Research and Service, UM VIDEOSHARE Outreach Project, 1989.

-This video was produced to give professionals, parents, and care providers a glimpse of the daily pressures that exist within a marriage when a child with disabilities becomes part of a family. This tape is accompanied by a three-page handout detailing strategies that parents and professionals can use to help a marriage survive.

- One hour
- $40.00
- 20-day preview period: non-refundable $20.00 fee to be applied to purchase price.

Daycare for Our Kids: Parents of Children with Special Needs. Parent Panel Moderator: Jan Spiegle. Division of Educational Research and Service, UM VIDEOSHARE Outreach Project, 1991.

-This tape was produced during a parent panel discussion for community daycare providers. Parents of children with special needs address questions from professionals and daycare providers pertaining to integration into daycare settings.

- Two hours
- $20.00
- 20-day preview period: non-refundable $10.00 fee to be applied to purchase price.

Play:Just Being a Kid. Susan Harper-Whalen. DERS, UM VIDEOSHARE Outreach Project, 1989.

-This presentation focuses on play and how children can learn to grow and achieve while having fun in a relaxed environment. Ms. Harper-Whalen is the Director of the University of Montana, Department of Education Early Childhood Center.

- One hour
- $20.00
- 20-day preview period: non-refundable $10.00 fee to be applied to purchase price.

Siblings of Children With Disabilities. Tom Powell. Eastern Montana College and the Division of Educational Research and Service, UM VIDEOSHARE Outreach Project, 1989.

-This presentation focuses on siblings and the perspectives of a father who has a teenage child with disabilities.

- One hour and 30 minutes
- $20.00
- 20-day preview period: non-refundable $10.00 fee to be applied to purchase price.

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Missoula, MT 59812
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